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# Romantic Relationships in Young People with Long-Term Health Conditions: A Scoping Review

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## Abstract

**Objective:** Forming and maintaining romantic relationships is an important developmental task in adolescence and young adulthood. This scoping review seeks to explore how young people with long-term physical health conditions understand and experience romantic relationships.

**Methods:** Using Arksey and O'Malley's scoping review framework, a systematic search of five databases was conducted (PsychINFO, Cinahl, MEDLINE, Embase and Web of Science). Studies were eligible for inclusion in the review if they were published in peer-reviewed journals, used primary data collection methods and adopted quantitative, qualitative, or mixed-methods approaches to study romantic relationships in 11-25 year olds with long-term physical health conditions. Using a data extraction form, data pertaining to demographic characteristics of young people with long-term physical health conditions and relationship engagement were extracted from eligible papers.

**Results:** Searches returned 4645 papers after duplicate removal, with a two-stage screening process resulting in 111 full text papers being reviewed. Thirty-three eligible papers were included across a range of long-term physical health conditions. Findings identified that living with a long-term physical health condition impacted young people's perceptions and experiences of romantic relationships across the relationship lifespan, from envisaging future relationships, to forming relationships and sustaining relationships. Issues around body confidence and self-esteem were identified as challenging in terms of perceptions and experiences of romantic relationships.

**Conclusions:** Findings demonstrate that young people wish to engage with romantic relationships, yet many report particular challenges associated with forming and sustaining relationships due to the constraints of their condition and treatment. Future research should consider non-heterosexual relationships.

## Introduction

Adolescence and young adulthood is/are developmental timepoints typically characterised by good health and positive well-being, although a substantial number of young people live with a long-term physical health condition (e.g., epilepsy, cancer). Long-term physical health conditions (LTC-P) are typically defined as physical health conditions with no expected cure that endure for three months or longer and impact on individuals' abilities to participate in everyday activities (Moore et al., 2019).

Research studies have addressed the impact of living with a LTC-P on young people's physical, social and psychological wellbeing (Moore et al., 2019; Shaw et al., 2019). With regard to health-related quality of life (HRQOL), a recent meta-analysis identified reduced levels of HRQOL across numerous domains in young people with LTC-P compared with condition free peers (Pinquart, 2020). Specifically, findings have identified reports of elevated levels of anxiety and depression in comparison with peers without LTC-Ps (Cobham et al., 2020; Pinquart & Shen, 2011; Stapersma et al., 2019). Notably, Maes et al.'s (2017) meta-analysis revealed significantly higher levels of loneliness in young people with LTC-P compared with condition-free peers. Young people with LTC-Ps report difficulties with school attendance, performance and engagement (Lum et al., 2017), establishing and maintaining peer relationships (Carter et al., 2020) in addition to disruptions to self-identity (Kirk & Hinton, 2019) and reduced levels of self-esteem (Pinquart, 2013).

Alongside LTC-P specific challenges which may require greater assistance from parents or caregivers in the home or other settings (Waldboth et al., 2016), young people also face normative challenges and key developmental tasks (e.g., establishing autonomy from parents and identity development) associated with transition into young adulthood. Heightened self-consciousness and self-conscious emotions associated with adolescence may influence a young person's confidence to perform in social situations (Somerville, 2013), adding further challenge to developing romantic relationships, a key developmental task (Kansky & Allen, 2018). A lack of intimate relationships is associated with reduced levels of well-being across the life span (Kiecolt-Glaser & Newton, 2001).

The idea of romantic relationship ‘success’ is complex. Over the course of adolescence and young adulthood, individuals move away from engaging in shorter term (dating) relationships and towards engaging in committed long term relationships (Kansky & Allen, 2018). Romantic success has previously been proposed as being in a committed (married or engaged) relationship before the age of 26 years (Schulenberg et al., 2004).

As little is known regarding romantic relationships in young people with LTC-P, a scoping review was specifically chosen to map the literature and generate an overview of the evidence (Munn et al., 2018). This scoping review aims to address an important knowledge gap concerning how young people with LTC-Ps understand and experience romantic relationships by identifying:

- (1) what is known in this area;
- (2) gaps in the literature; and
- (3) directions for future research concerning romantic relationships for young people with LTC-Ps.

We deliberately selected a broad age range (11-25 years) to be as inclusive as possible given the evidence suggesting the extension of adolescence into the early-mid twenties (Sawyer et al., 2018). This protocol was pre-registered (<https://osf.io/7bkvm/>).

## **Method**

A scoping review, guided by Arksey and O’Malley’s (2005) scoping review framework was undertaken to identify, map and synthesise the literature concerning romantic relationships experienced by young people with LTC-Ps. This framework comprises five distinct phases which are detailed below.

### **Stage 1: Identification of the Research Question**

The review addressed the following research question: What is known about how young people perceive and report experiences of romantic relationships in the context of living with a long-term physical health condition?

### **Stage 2: Identification of Relevant Studies**

In accordance with the guidance provided by (Arksey & O’Malley, 2005) we initially conducted a broad search to identify all relevant studies of interest. The search captured three main concepts: (1)

romantic relationships, (2) long term (chronic) physical health conditions and (3) young people. The electronic searches were performed by an information specialist (K.F.) on May 1<sup>st</sup>, 2019 in the databases MEDLINE(R) ALL (Ovid, 1946 to April 30, 2019), EMBASE (Ovid, 1947 to April 30, 2019), PsycInfo (Ovid, 1806- April Week 4, 2019), CINAHL (EBSCOhost, 1976 to 2019), and Web of Science (1900-2019). All databases were searched from their inception. Studies were identified using a combination of each of the databases' unique subject headings and keywords. Concepts pertaining to age (e.g. youth, emerging adult), long-term physical health condition (e.g. arthritis) and romantic relationships (e.g. partner, boyfriend) were searched. Only human empirical studies were included, with no limits to study designs, for a result of 6,245 references retrieved. Using Covidence software and EndNoteX9 1,600 references were removed; a total of 4,645 citations sent to the screening stage. Please see Supplementary Tables 1-2 for full search strategies.

### **Stage 3: Study Selection**

All citations were uploaded to Covidence systematic review software (Veritas Health Innovation, n.d.) Screening followed a two-step process, involving a screening and eligibility phrase (Figure 1).

#### **Screening: Step 1**

Titles and abstracts of the 4645 citations were initially screened by independently trained research assistants using clear inclusion and exclusion criteria (Table 1). Studies were eligible for inclusion in the review if they: (1) were published in peer-reviewed journals, (2) used primary data collection including quantitative, qualitative, or mixed-methods approaches, (3) studied populations comprising 11-25 year olds with LTC-P and (4) reported on romantic relationships. Studies were excluded if they included participants with a primary diagnosis of cognitive impairment, a primary focus on mental health conditions, or focused on platonic friendships and peer relationships. Conflicts at this stage were addressed by P.F resulting in the exclusion of 4450 records; 195 records remained for the second round of screening.

Insert Figure 1 and Table 1 about here

#### **Screening: Step 2**

To ensure that identified articles would be sufficiently focused on the topic, the authors adjusted the eligibility criteria in the second screening round. The revised screening was more tightly focused on romantic relationships rather than studies which only reported on sexual functioning. This adjustment is congruent with scoping review guidance (Arksey & O'Malley, 2005) which proposes researchers may adjust screening criteria post hoc once they are more familiar with the range of topics within the literature. Consequently, new *exclusion* criteria were added to tighten screening. These new exclusion criteria comprised studies which (1) have a dominant focus on sexual activity or functioning and (2) studies in which findings for a wider population group are *not* reported separately for participants aged 11-25 years.

The second round of title and abstract screening was conducted by three authors (AJ, BC and PF), with all abstracts in this round independently screened by two of these authors. Conflicts were resolved by whichever of these authors did not screen that particular abstract, resulting in 84 articles being excluded, and 111 articles progressing to full text review.

### **Full text review**

All full text articles were independently reviewed by two of three authors (AJ, BC and PF). Any disagreement about eligibility of any study during full text review was addressed by the remaining author who did not screen the full text of the study (AJ, BC or PF). A total of 77 articles were excluded at the full-text stage. Articles were excluded for the following reasons: (1) ineligible age range (n=62), (2) insufficient focus on romantic relationships (n=5), ineligible format such as conference poster or review (n=10), and (4) insufficient focus on young people with a long health term condition (n=1).

Additionally, all retrieved reviews were hand searched to ensure that no relevant studies were missed. Google Scholar was also searched to conduct forward and backward citation searches for all eligible studies. Neither of these two strategies identified any further papers.

### **Stage 4: Charting the Data**

A data extraction form was developed by the research team (available on request from the lead author). Data extraction was conducted by KS and reviewed by a second author (e.g. AJ, BC or PF).

For each study, information was selected regarding study authors and title, year of publication, journal, study aim/research question, methodological approach (e.g. qualitative, quantitative, mixed methods), participant recruitment (recruitment method), sampling (sample size, gender, age of participants), location (country of study), methods (e.g. survey, focus group, interview, observational study) and specific nature of the romantic relationship studied (e.g. partner, boyfriend/girlfriend, spouse, perceived future relationship), and health status of the respondents (e.g. nature of long-term condition, normative comparison group). Narrative methods and tables were used to chart the data.

### **Appraisal of study quality**

The Mixed Methods Appraisal Tool MMAT (Hong et al., 2018) was used to review, but not score, the methodological quality of all 33 included articles. The MMAT was selected as it enables robust assessment of quality across a range of study designs and study elements with a single tool. Specifically, the calculation of an overall quality score from each MMAT criterion is discouraged. Psychometric evaluation of the MMAT has identified moderate to perfect agreement between reviewers for the MMAT criteria and substantial agreement in terms of the overall quality score of studies reviewed using the tool (Pace et al., 2012).

Quality screening for all articles was conducted by KS and reviewed by a second author (AJ, BC or PF). Findings pertaining to study quality are presented in Table 2. Of the 33 articles, 21 did not phrase their research aim in the form of a question. Typically, qualitative articles met the assessment criteria more robustly (as noted by a higher number of yes responses to individual criteria) than the articles using other methodologies. Key quality issues related to reporting of incomplete outcome data, insufficient information presented to determine if the measurements or analyses were appropriate, or if the risk of non-response bias was low.

Insert Table 2 about here



## **Results (Stage 5: Collating, Summarizing and Reporting the Results)**

### **Overview of studies**

A condensed summary chart detailing the study design, sample, requirements, setting and delivery can be found in Supplementary Table 3. The review of studies via the MMAT revealed the quality as fair (see Table 2). Data were international, reporting on studies which recruited samples from the USA (n=14), Netherlands (n=8), United Kingdom (n=5), Germany (n=2), Canada (n=2), Norway (n=2), Australia (n=1), Finland (n=1), Italy (n=1), France (1), Poland (1) and Israel (n=1). Studies included in the review adopted the following research designs: quantitative descriptive (n=16), quantitative nonrandomised (n=8), quantitative randomised controlled trial (n=1), mixed methods (n=1), and qualitative (n=7). Sample sizes of young people with a LTC-P ranged from 5-758. Papers investigated a total of 22 long-term conditions, the most frequent being cancer (n=9) and spina bifida (SB) (n=8). Please see Table 3 for further information about the conditions.

Insert Table 3 about here.

## **Results**

Three key themes were identified which summarised the perceptions and experiences of young people with LTC-Ps around engagement with romantic relationships. These themes comprise (1) envisaging romantic relationships, (2) forming romantic relationships and (3) sustaining romantic relationships. The thread of 'sense of self' was interwoven throughout each of the themes. Findings are not categorised by condition as our focus was on young people, rather than conditions per se. However, we report on the conditions within the findings. A synthesis of key findings in each theme and corresponding sub-theme will be presented below. Specific details of relationship characteristics and contrasts with comparison groups can be found in Supplementary Table 4.

Insert Figure 2 about here

### **Envisaging Romantic Relationships**

Ten studies explored young people's views concerning their desire and perceived ability to engage with relationships across the lifespan. Typically, young people reported positive perceptions

regarding their ability to be involved in relationships at all time points, ranging from early romantic relationships (Dorner, 1977) to marriage and having children (Blum et al., 1991; Zani et al., 1995).

### **Envisaging/Hoping for a romantic relationship**

Young people reported a desire to be involved in future romantic relationships, with 80% of young people with SB expressing an interest in the opposite sex (Dorner, 1977). Young people with SB reported significantly higher perceptions of being involved in future romantic relationships compared with parents (Sawin et al., 2006). Conversely, being in a romantic relationship was not a priority for young people with cancer; although these individuals worried that cancer may negatively impact romantic relationships, citing diminished self-esteem and other psychological impacts as reasons why relationships may be difficult (Stinson et al., 2015).

### **Envisaging/Hoping for marriage**

Overall, studies identified young people's positive perceptions and aspirations of marriage, with individual study findings possibly indicative of the specific nature of the LTC-P, e.g., SB (Blum et al., 1991; Dorner, 1977), arthritis (Gerhardt et al., 2007) and thalassaemia (Zani et al., 1995). No differences in aspirations of marriage were noted between young people with cancer and their peers (Gerhardt et al., 2007). Many young people with SB (Dorner, 1976), cerebral palsy (CP) (Blum et al., 1991), and thalassemia (Zani et al., 1995), either had aspirations of marriage or considered marriage to be important. However, some young people with SB who envisaged marriage doubted it would happen (Dorner, 1976). One study noted that greater initial (cancer) treatment intensity was associated with having future aspirational plans of marriage (Gerhardt et al., 2007).

### **Envisaging/Hoping for family/children**

Some young people with SB reported wishing to have children (Blum et al., 1991) or perceived this as important as their peers (Zani et al., 1995). In comparison with peers, young people with juvenile idiopathic arthritis (JIA) less frequently reported having children as being a long-term goal (Gerhardt et al., 2011). No differences in future family plans were noted between young people with cancer and peers (Gerhardt et al., 2007).

## **Envisaging/Hoping for sexual relationships**

A single study identified that adolescents with bladder exstrophy reported feeling positive about their desire and ability to be involved in future sexual relationships (Wilson et al., 2007).

## **Forming Romantic Relationships**

Seventeen studies considered aspects of forming romantic relationships; these relationships were formed through dating. Dating was seen variously, as just being normal by young people with SB (Heller et al., 2016), and for young people with cancer as a challenge (Thompson et al., 2013) or a source of support (Stinson et al., 2015).

### **Dating**

Some studies showed that young people with allergies, diabetes, asthma, migraines, non-allergic skin conditions (Bussing & Aro, 1996), and JIA (Gerhardt et al., 2007) did not perceive themselves as being that different to their peers in relation to dating, although this was not evident across all studies. Many of the young people with JIA, did not identify challenges (Secor-Turner et al., 2011) and some with CP just got on with dating (Wiegerink et al., 2008), reporting being similarly popular to their peers (Gerhardt et al., 2011), and as successful in forming relationships (Behle & Pinquart, 2015) despite living with various different conditions. Most who had conditions ranging from food allergies (Hullmann et al., 2012) to CP (Wiegerink et al., 2008) had been on a date/in a dating relationship and/or been in love (Wiegerink et al., 2008); no significant gender differences were found between young people with SB (Verhoef et al., 2005) or CP (Wiegerink et al., 2008). However, higher levels of physical restrictions as experienced by those with neurological disabilities were associated with significantly lower perceived attainment of romantic relationships (Behle & Pinquart, 2015), difficulties in forming relationships (Dorner, 1976; Verhoef et al., 2000) or lower levels of dating than their healthy peers (Blum et al., 1991; Zukerman et al., 2011). Cancer survivors reported challenges connecting with and forming close relationships with others including romantic partners (Thompson et al., 2013).

### **Factors that influenced dating**

Although Behle and Pinquart's (2015) study of young people with a range of conditions (e.g. SB, orthopedic conditions) perceived themselves to be as successful at forming romantic relationships as their peers, three broad categories of factors were identified in other studies that influenced dating: symptom/disability-related, confidence-related and opportunity-related. Symptom/disability related factors included the disruption caused by fatigue and nausea associated with cancer (Stinson et al., 2015) or physical disabilities and wheelchair dependency associated with CP (Wiegerink et al., 2008). Confidence related factors differed across conditions, young people with gastrointestinal disorders (e.g. inflammatory bowel disease, chronic liver disease) reported feeling less confident (Calsbeek et al., 2002), those with CP were concerned about being treated differently (Wiegerink et al., 2008) and young people with cancer reported body image and self-esteem issues (Sodergren et al., 2018). Opportunity-related factors for those with cancer included limited opportunities to discuss relationships with peers (Martins et al., 2018) or to establish romantic relationships (Sodergren et al., 2018) that could result from time spent receiving cancer care or stigma associated with being ill (Stinson et al., 2015). For young people with SB having more friends and contact with mixed gender peers resulted in more dating (Wiegerink et al., 2010b).

### **Disclosure**

Overall young people felt inhibited, reluctant or worried about disclosing their condition and sharing personal thoughts/feelings with others and communicating its impacts to their partner (Dorner, 1977; Heller et al., 2016; Thompson et al., 2013). This was linked to a fear of rejection by those with SB (Dorner, 1977) or bladder exstrophy (Wilson et al., 2007) or concern that friends would not understand their JIA (Secor-Turner et al., 2011). Some young people with SB reported being worried about how and when to disclose their condition (Heller et al., 2016). Some disclosure related reluctance was linked to protecting loved ones from the reality of their cancer condition (Thompson et al., 2013). However, of those with SB who did disclose, some gained confidence in themselves and their relationship (Heller et al., 2016) and positive benefits included better support. This was the case for some young people with bladder exstrophy who had not felt in control of the disclosure (Wilson et al., 2007).

## **Sustaining Romantic Relationships**

Eighteen studies addressed issues of sustaining romantic relationships, typically with significant others. Young people reported various positive and negative impacts of living with a LTC-P on their ability to sustain romantic relationships.

### **Relationship (likelihood of being in a current relationship)**

When comparing groups of young people with LTC-Ps with normative samples, a number of studies such as those focusing on young people with cancer identified similar levels of dating and having a 'significant other' among young people with LTC-Ps and those without (Gerhardt et al., 2011; Gerhardt et al., 2007). However, this was not the case for all, with young people living with food allergy (Hullmann et al., 2012), CP (Wiegerink et al., 2010b) and cleft lip/palate (Feragen et al., 2016) identifying lower rates of being in a current relationship compared with condition free peers. Findings identified a multitude of factors which may influence young people's ability to engage with relationships, including the severity of the condition, comorbidity, gender and nature of treatment (Feragen et al., 2016; Thompson et al., 2009). Notably, young people who had survived high-intensity cancer treatment (Thompson et al., 2009) reported fewer previous relationships as did females with cleft lip/palate (Feragen et al., 2016) than a normative comparison group. Cognitive factors were also important, with young people with diabetes reporting higher scores on optimism, mastery and self-blame measures more likely to be in a romantic relationship (Helgeson et al., 2014).

### **Positive experiences of relationships**

Young people with cancer described positive changes in their relationship with a significant other as a result of living with a LTC-P (Bellizzi et al., 2012). Specifically, cancer 'survivors' described how an altered perspective on life gained during treatment positively impacted their romantic relationships (Thompson et al., 2013). For these young people, emotional support provided by partners during treatment enabled them to better manage their cancer, with supportive partner relationships characterised by good communication and low conflict (Robertson et al., 2016).

## **Negative aspects of relationships**

Many studies detailed the negative impact of living with a LTC-P on young people's romantic relationships. Negative impacts included increased rates of disordered eating in young people with diabetes who reported high levels of relationship conflict (Helgeson et al., 2015), increased distress at the end of the relationship for those with cancer (Thompson et al., 2009), and elevated levels of relationship conflict for those with conditions ranging from allergies to asthma (Bussing & Aro, 1996) when compared with normative samples. One study identified low levels of relationship satisfaction in some young cancer survivors, predicted by factors including older age at cancer diagnosis, higher trait anxiety and more severe treatment (Thompson et al., 2009). However, such experiences were not universal, some young people with diabetes reported similar levels of relationship conflict to peers (Helgeson et al., 2015; Seiffge-Krenke, 1997).

## **Marriage**

Studies describing marriage statistics were varied in terms of findings. One study identified similar levels of marriage among young people with cancer and their peers (Gerhardt et al., 2007). Conversely, a large study of young people with a variety of LTC-Ps identified that young women with LTC-P were more likely to be married or living with a partner than condition free peers (Bussing & Aro, 1996).

## **Family/children**

Typically, young people living with SB and other neurologic conditions reported a desire to have children in the future (Verhoef et al., 2005), yet only a few young people with CP or SB reported not wishing to have children (Blum et al., 1991). Whilst many desired children in the future, some young people reported having to put plans for parenthood on hold due to the constraints associated with managing their cancer (Bellizzi et al., 2012; Sodergren et al., 2018). A common concern related to the impact of their condition on their ability have children such as reduced fertility and limited fertility preservation options, particularly for those living with cancer (Stinson et al., 2015; Thompson et al., 2013). Further concerns about having children focused on anxieties around having a child with a

disability and not finding anyone to have a child with were reported by those with SB (Blum et al., 1991). Of the young people with a LTC-P who already had children, the age at which they became parents was similar to that of peers (Bussing & Aro, 1996).

### **Sexual functioning and intimacy**

A key aspect of sustaining relationships concerned the ability and desire to engage in sexual intercourse. In some studies, a minority of young people with CP (Wiegerink et al., 2008), diabetes (Seiffge-Krenke, 1997) and cancer (Stinson et al., 2015), reported their condition to currently, or in the future, affect their ability to enjoy a fulfilling sexual relationship. Whereas the effects of living with a LTC-P on sexual functioning and desire were found to be greater in other studies. Specifically, young people reported reduced satisfaction with their sex life, alterations in patterns of intimacy with partners, and resulting strain on their partner (Bellizzi et al., 2012; Hullmann et al., 2012; Robertson et al., 2016; Seiffge-Krenke, 1997; Sodergren et al., 2018; Verhoef et al., 2005). Reported challenges to engaging in sexual relationships were often condition/symptom specific, including incontinence and reduced self-esteem in the case of young people with SB (Verhoef et al., 2005).

### **Sense of Self**

Eleven studies explored young people's sense of self and how this impacts on their ability to develop and sustain relationships. For some young people with CP, greater self-esteem and sense of competence were associated with being in a current relationship (Wiegerink et al., 2012). However, young people with cancer reported a sense of difference compared with peers in terms of their priorities, which impacted both negatively and positively on their ability to develop and sustain romantic relationships (Thompson et al., 2013).

Although not affecting all young people, some with SB reported that their LTC-P made them worry about relationships (Dorner, 1977). Young people with SB (Dorner, 1976; Heller et al., 2016), digestive disorder (Calsbeek et al., 2002) and bladder exstrophy (Wilson et al., 2007) were specifically anxious about rejection. Impact on self-confidence was reported by young people with SB (Verhoef et al., 2000), CP (Wiegerink et al., 2008) and bladder exstrophy (Wilson et al., 2007). Impact on body

image was noted by young people with CP (Wiegerink et al., 2008), cleft lip and palate (Feragen et al., 2016) and cancer (Martins et al., 2018; Thompson et al., 2013). Anxiety about rejection could prevent young people from engaging in casual or sexual relationships and was typically associated with the functional impact of their LTC-P such as low energy levels associated with cancer (Martins et al., 2018), functionality of genitals for those with bladder exstrophy (Wilson et al., 2007), and issues associated with incontinence and appliances for managing incontinence (Dorner, 1976; Heller et al., 2016; Verhoef et al., 2000).

Lack of self-confidence was an obstacle to forming relationships for young people with SB (Verhoef et al., 2000), CP (Wiegerink et al., 2008), bladder exstrophy (Wilson et al., 2007) and to moving onto greater physical intimacy for those with digestive disorders (Calsbeek et al., 2002), SB (Verhoef et al., 2000) and bladder exstrophy (Wilson et al., 2007). Some studies reported that negative body image related to cancer impacted on romantic relationships and the development of intimacy and/or sexual relationships (Martins et al., 2018; Thompson et al., 2013). However, other studies reported that physical characteristics for those with CP (Wiegerink et al., 2010a) were not associated with their dating experience, nor perceived romantic appeal for those with cleft lip and palate repair (Feragen et al., 2016). Some young people with CP reported their physical appearance similar to reference values and their body esteem as higher in comparison to persons with other physical disabilities (Wiegerink et al., 2008). One study found that the body confidence of young people with cancer could be enhanced through an intervention (Canada et al., 2007).

## **Discussion**

This scoping review of 33 eligible studies systematically examined empirical evidence pertaining to how young people (11-25 years; n= 5-578 participants) with a range of 22 LTC-Ps perceive and engage with romantic relationships. To our knowledge, this is the first scoping review to explore the issue of romantic relationships in young people across a range of LTC-Ps. Most papers adopted a quantitative approach to studying romantic relationships. With regard to addressing the research questions, overall study findings identified that living with a LTC-P impacted on young



people's perceptions and experiences of romantic relationships across the relationship lifespan, from envisaging future relationships, to forming relationships, sustaining relationships and sexual relationships. Only 4 studies addressed LGBT relationships.

Findings in this review identified both similarities and differences with regard to young people's perceptions and experiences of romantic relationships between LTC-Ps. For example, differences included young people with conditions such as SB and those with associated bowel and bladder functioning related issues reporting unique concerns about disclosure of their condition (Heller et al., 2016; Wilson et al., 2007; Dorner et al., 1977) which were not reported by young people with other LTC-P. Additionally, condition specific differences included young people living with cancer reporting positive aspects associated with their condition such as an altered perspective on life (Thompson et al., 2013), but also anxieties related to implications for subsequent fertility based on cancer related treatment (Stinson et al., 2015; Thompson et al., 2013). Such findings were not reported for other groups of young people with LTC-P in this review. Despite such differences, similarities across LTC-P (e.g. SB, arthritis and cerebral palsy) were reported in terms of young people's perceptions of and aspirations to marry in the future (Blum et al., 1991; Dorner, 1977; Gerhardt et al., 2007; Zani et al., 1995). Relatedly, findings in this review identified a collective sense of similarity to peers in relation to dating among young people with a variety of LTC-Ps including allergies, diabetes, asthma, migraines, non-allergic skin conditions and JIA (Bussing & Aro, 1996; Gerhardt et al., 2007).

Review findings highlighted that young people with LTC-P wish to engage with romantic relationships, with some reporting particular challenges associated with forming and sustaining relationships due to the constraints of their condition and treatment. This strong desire to be connected romantically to another individual is particularly important during adolescence and young adulthood, where the social function of the brain further develops (Blakemore, 2008) and social connections with others (e.g. peers) become more critical for young people (van Harmelen et al., 2017). Also, forming and sustaining romantic relationships is recognised as "one of the critical developmental tasks marking

one's entry into adulthood" (Rauer et al., 2013), highlighting the importance of being able to successfully engage in romantic relationships for young people with LTC-Ps.

A particular barrier for young people with LTC-Ps in terms of their ability to envisage, form and sustain romantic relationships concerned reported low levels of self-esteem and body confidence. An association between self-esteem and successful romantic relationship engagement in youth has also been identified in the normative literature (Luciano & Orth, 2017). Yet, young people with LTC-Ps face additional related challenges associated with condition specific symptoms or treatment(s) which may distinguish them as perceiving themselves to be, or appearing different to peers and prospective romantic partners (Cartwright et al., 2015). This may exacerbate the effects of self-esteem on young people to envisage and engage with romantic relationships whilst living with an LTC-P.

Related to the issue of self-esteem, review findings identified the issue of disclosure of the condition as being difficult for many young people with LTC-Ps in terms of their ability to form relationships. This is unsurprising as literature has identified stigmatisation of particular groups of adolescents including those who are obese (Pont et al., 2017) and those with mental health disorders (Kaushik et al., 2016). Despite perceived stigma, disclosure of a health condition in romantic relationships is associated with access to social support in addition to physical and psychological wellbeing for individuals who disclose (Carter et al., 2020; Greene et al., 2012). However, little is known concerning how young people struggle to know how and when to disclose details of their condition to potential partners. As findings in this study identified, this can be a barrier to forming romantic relationships and a particular challenge for engaging with sexual relationships. Consequently, such findings identify an important gap in the literature and direction for future research.

### **Strengths and Limitations**

This review adopted a broad strategy to examine romantic relationships across a wide range of LTC-Ps in young people, enabling comparison of findings across different conditions to identify common challenges associated with young people's experiences of romantic relationships. With regard to limitations, one particular issue we identified pertained to the age groups studied. Our inclusion

criteria required participants to be aged 11-25 years or include data split for this age group. This resulted in the exclusion of potentially relevant studies that did not report data separately from the older age groups studied. This is reflective of the lack of consistency regarding terms to describe individuals aged 11-25 years (e.g. young people, youth, adolescents or young adults) and the fluidity in age for such age groups across studies. Given the substantial developmental differences across adolescence, early-adulthood, adulthood and beyond, it is essential that future studies specifically report findings for specific age group bands if they choose to use a sample comprising young people from wide-ranging age ranges across adolescence, young adulthood and adulthood (e.g. 15-40 years). A final limitation concerns the comprehensiveness of the search strategy. It is important to note that the search strategy did not include terms relating to obesity or neurodevelopmental conditions if cognitive impairment was the primary focus (e.g. young people with brain cancer). Consequently, it will be important for future reviews to focus specifically on young people who live with these specific conditions and their experiences, and those of their partner, of romantic relationships.

### **Implications for Research**

This review aimed to identify gaps in the research worthy of future study. First, a knowledge gap was identified concerning studies focusing on lesbian, gay, bisexual and transgender relationships (LGBT) relationships, with only four studies including young people with LGBT relationships. Of these four studies, two of them simply reported the sexual preference of young people with CP (Wiegerink et al., 2008) and SB (Verhoef et al., 2005). It is likely that this reduced focus on LGBT relationships may be explained by inclusion of older studies which were conducted in times characterised by reduced acceptance of LGBT relationships. However, it is critical to develop literature that is inclusive of young people's perceptions and experiences of all romantic relationships, with a specific focus on LGBT relationships since rates of identification as gay, lesbian or bisexual are higher in young people aged 16-24 years (4.2%) than in the general population (2%) (Hagell & Shah, 2019).

Second, this review identified an important issue concerning the dominant focus of existing literature on studying only one individual within a relationship dyad. In our review, none of the eligible studies included partners as study participants. Omitting partners ignores that romantic relationships

exist within a relationship context. To address this knowledge gap studies are needed that explore how partners perceive and understand relationships in the context of a young person living with a LTC-P. Following the work of Furman & Shomaker (2008) in normative populations, future studies should adopt dyadic approaches to examine relationship functioning between young people with LTC-Ps and their partner.

Third, we suggest future research examine the topic of perceptions and engagement with romantic relationships according to age sub-groups, with a specific need for longitudinal research to examine whether adolescents diagnosed with LTC-P prior to or during early adolescence adapt to their condition and perceive fewer impacts on their ability to engage with romantic relationships compared with those diagnosed later.

Fourth, we suggest adopting a cautious approach in future studies with regard to considering the issue of categorising conditions in terms of difference or assumed impact due to limitations of this approach. For example, an apparently simple binary categorisation of conditions into those which are invisible and those which are visible, can be challenged as largely invisible conditions such as Crohn's disease can become visible at times due to interventions and treatments. Conversely, some apparently visible conditions such as cerebral palsy may not be overtly visible or may be masked. Other categories such as the likelihood of stigma (e.g., issues with continence, dramatic changes to body image) may or may not have an impact on the individual depending on protective factors inherent to the individual. Also, some issues such as the impact on body image will be identified across conditions. Consequently, condition-specific differences may not be as clear as might first be assumed. Future research needs to adopt a more inclusive approach across LTC-P populations to critically examine with young people what they perceive to be influencing their romantic relationships and to what degree they believe this is condition-specific or influenced by other factors.

Finally, despite a lack of consensus regarding use of appropriate measures to examine how young people with LTC-P perceive and experience romantic relationships, we offer some suggestions for use of relevant measures in future studies. For example, use of the Self-Perception Profile for

Adolescents (Harter, 1988) can be helpful as this measure includes sub-scales focused on assessing adolescent self-perceptions of romantic appeal, physical appearance and self-worth. The Self-Perception Profile for Adolescents demonstrates appropriate psychometric properties for use with normative populations of young people and good levels of internal consistency with young people with specific LTC-P such as myelomeningocele (Sawin et al., 2016). For studies wishing to use a more dating specific measure, the Dating Anxiety Scale for Adolescents (Glickman & La Greca, 2004) may be of use. This measure has been shown to possess acceptable levels of reliability and validity for use with adolescents who do not live with LTC-P and good levels of internal consistency with young people with specific LTC-P such as with food allergies (Hullman et al., 2012). The lack of age appropriate measures focused specifically on examining the perceptions and experiences of romantic relationships among young people with LTC-P suggests a clear need for the development of an age appropriate psychometrically robust measure to address this important measurement gap.

### **Implications for Practice**

Findings in this review show the importance that young people ascribe to thinking and engaging with romantic relationships in addition to some of the particular challenges they face with this due to their LTC-P and associated treatment. Results suggest tentative evidence to support including psychological and social strategies when working with young people with LTC-P. For example, within or in addition to clinical encounters, young people need an opportunity to engage in discussion of these issues, particularly around how and when to disclose to potential or existing romantic partners about their LTC-P. Additional issues which could warrant intervention in clinical settings include strategies to help young people with cancer understand fertility issues and issues of managing incontinence for young people with conditions such as SB and the relationship of these factors to their ability to foster and engage in romantic relationships.

### **Conclusion**

Review findings demonstrate that most young people with physical LTC-P both wish to, and do engage with romantic relationships despite facing particular challenges which relate to living with a

LTC-P. Future research needs to address LGBT relationships, partner effects, and present findings for developmental age bands across studies with wide age ranges to inform intervention strategies.

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**Table 1: Study Inclusion and Exclusion Criteria**

Inclusion criteria	Exclusion criteria
<ol style="list-style-type: none"> <li>1. Empirical studies (qualitative, quantitative, mixed methods),</li> <li>2. Written in the English language,</li> <li>3. Published in peer reviewed journals,</li> <li>4. Focused on individuals with long term physical health conditions</li> <li>5. Participants aged 11-25 years</li> <li>6. Focused on the topic of romantic relationships (any same or opposite sex relationship in which there is romantic involvement).</li> </ol>	<ol style="list-style-type: none"> <li>1. Studies which did not include collection of primary data (e.g. reviews, editorials, letters, conference proceedings, case reports, commentaries, books, and book chapters)</li> <li>2. Studies in which participants had a diagnosis of cognitive impairment. (e. g. Down's syndrome, degenerative disorders with developmental delay, and Traumatic Brain Injury)</li> <li>3. Populations in which the primary focus is on mental health conditions in young people (e.g. Depression, Anxiety, Obsessive Compulsive Disorder, Post-Traumatic Stress Disorder, Schizophrenia, Personality Disorders)</li> <li>4. Studies which focused on examining platonic friendships and peer relationships</li> </ol>

**Table 2: Quality Appraisal of Papers Using Mixed Methods Appraisal Tool (Hong et al., 2018)**

Author	Screening questions		Qualitative criteria				
	Are there clear research questions?	Does data address the research	Is qualitative approach appropriate?	Are qualitative data collection methods adequate?	Are findings adequately derived from the data?	Is interpretation of results substantiated by data?	Is there coherence across all stages of study?
Heller et al. (2016)	Yes*	Yes	Yes	Yes	Yes	Yes	Yes
Martins et al. (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Secor-Turner et al. (2011)	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sodergren et al. (2018)	Yes*	Yes	Yes	Yes	Yes	Yes	Yes
Stinson et al. (2015)	Yes*	Yes	Yes	Yes	Yes	Yes	Yes
Thompson et al. (2013)	Yes*	Yes	Yes	Yes	Yes	Yes	Yes
Wilson et al. (2007)	Yes*	Yes	Yes	Yes	Yes	Yes	Yes
<b>Quantitative randomised controlled trial criteria</b>							
			Is randomization appropriately performed?	Are the groups comparable at baseline?	Are there complete outcome data?	Are outcome assessors blinded to intervention provided?	Did participants adhere to the assigned intervention?
Canada et al. (2007)	Yes*	Yes	Yes	Yes	No	No	CT
<b>Quantitative nonrandomised criteria</b>							
			Are participants representative of target population?	Are measurements appropriate re outcome & intervention?	Are there complete outcome data?	Are confounders accounted for in the design and analysis?	Is intervention /exposure as intended?
Bussing & Aro (1996)	Yes*	Yes	Yes	Yes(p)	Yes	Yes	N/A
Feragen et al. (2016)	Yes*	Yes	Yes	Yes	No	Yes	N/A
Gerhardt et al. (2007)	Yes*	Yes	Yes	Yes	No	Yes	N/A
Gerhardt et al. (2011)	Yes*	Yes	Yes	Yes	No	Yes	N/A
Helgeson et al. (2014a)	Yes	Yes	Yes	Yes	No	Yes	N/A
Helgeson et al. (2014b)	Yes*	Yes	Yes	Yes	No	Yes	N/A
Hullmann et al. (2012)	Yes*	Yes	Yes	Yes	No	No	N/A
Zukerman et al. (2011)	No	Yes	Yes	Yes	Yes	No	N/A
<b>Quantitative descriptive criteria</b>							
			Is sampling strategy relevant?	Is sample representative of the target population?	Are measurements appropriate?	Is risk of nonresponse bias low?	Is statistical analysis appropriate?
Behle & Pinquart al.	Yes	Yes	Yes	Yes	Yes	CT	Yes
Bellizzi et al. (2012)	Yes*	Yes	Yes	No	Yes	No	No



Blum et al. (1991)	Yes*	Yes	Yes	Yes	Yes	CT	CT
Calsbeek et al. (2002)	Yes	Yes(p)	Yes	Yes	CT	No	Yes
Dorner (1976)	No	CT	Yes	Yes	CT	CT	CT
Dorner (1977)	Yes*	Yes	Yes	CT	CT	CT	CT
Sawin et al. (2006)	Yes*	Yes	Yes	Yes	Yes	CT	CT
Seiffge-Krenke (1997)	Yes	Yes	Yes	CT	Yes	CT	CT
Thompson et al. (2009)	Yes*	Yes	Yes	Yes	Yes	CT	Yes
Verhoef et al. (2000)	No	CT	Yes	CT	CT	Yes(p)	Yes
Verhoef et al. (2005)	No	Yes	Yes	Yes	CT	Yes	CT
Wiegerink et al. (2008)	No	Yes	Yes	Yes	Yes	CT	CT
Wiegerink et al. (2010a)	No	Yes	Yes	Yes	Yes	CT	CT
Wiegerink et al. (2010b)	Yes*	Yes	Yes	Yes	Yes	Yes	Yes
Wiegerink et al. (2012)	Yes*	Yes	Yes	Yes	Yes	Yes	Yes
Zani et al. (1995)	No	Yes	Yes	Yes	Yes	CT	CT
<b>Mixed methods criteria</b>							
			Is there an adequate rationale for using mixed methods?	Are different components of study effectively integrated?	Are the outputs of integration adequately interpreted?	Are inconsistencies results addressed?	Are quality criteria adhered to?
Robertson et al. (2016)	Yes*	Yes	Yes	Yes	Yes	CT	CT

Key: Y=Yes, Y\*=Yes but not explicitly written as a research question, Yes(p)=Yes but partial, CT=Can't Tell.

Note: Please note that the Yes\* 'Yes but not explicitly written as a research question' and Yes(p) are not part of the MMAT response criteria but are additional responses provided by the reviewers for the purposes of transparency.

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Secor-Turner et al. (2011)	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sodergren et al. (2018)	Yes*	Yes	Yes	Yes	Yes	Yes	Yes
Stinson et al. (2015)	Yes*	Yes	Yes	Yes	Yes	Yes	Yes
Thompson et al. (2013)	Yes*	Yes	Yes	Yes	Yes	Yes	Yes
Wilson et al. (2007)	Yes*	Yes	Yes	Yes	Yes	Yes	Yes
<b>Quantitative randomised controlled trial criteria</b>							
			Is randomization appropriately performed?	Are the groups comparable at baseline?	Are there complete outcome data?	Are outcome assessors blinded to intervention provided?	Did participants adhere to the assigned intervention?
Canada et al. (2007)	Yes*	Yes	Yes	Yes	No	No	CT
<b>Quantitative nonrandomised criteria</b>							
			Are participants representative of target population?	Are measurements appropriate re outcome & intervention?	Are there complete outcome data?	Are confounders accounted for in the design and analysis?	Is intervention /exposure as intended?
Bussing & Aro (1996)	Yes*	Yes	Yes	Yes(p)	Yes	Yes	N/A
Feragen et al. (2016)	Yes*	Yes	Yes	Yes	No	Yes	N/A
Gerhardt et al. (2007)	Yes*	Yes	Yes	Yes	No	Yes	N/A
Gerhardt et al. (2011)	Yes*	Yes	Yes	Yes	No	Yes	N/A
Helgeson et al. (2014a)	Yes	Yes	Yes	Yes	No	Yes	N/A
Helgeson et al. (2014b)	Yes*	Yes	Yes	Yes	No	Yes	N/A
Hullmann et al. (2012)	Yes*	Yes	Yes	Yes	No	No	N/A
Zukerman et al. (2011)	No	Yes	Yes	Yes	Yes	No	N/A
<b>Quantitative descriptive criteria</b>							
			Is sampling strategy relevant?	Is sample representative of the target population?	Are measurements appropriate?	Is risk of nonresponse bias low?	Is statistical analysis appropriate?
Behle & Pinquart al.	Yes	Yes	Yes	Yes	Yes	CT	Yes
Bellizzi et al. (2012)	Yes*	Yes	Yes	No	Yes	No	No

Blum et al. (1991)	Yes*	Yes	Yes	Yes	Yes	CT	CT
Calsbeek et al. (2002)	Yes	Yes(p)	Yes	Yes	CT	No	Yes
Dorner (1976)	No	CT	Yes	Yes	CT	CT	CT
Dorner (1977)	Yes*	Yes	Yes	CT	CT	CT	CT
Sawin et al. (2006)	Yes*	Yes	Yes	Yes	Yes	CT	CT
Seiffge-Krenke (1997)	Yes	Yes	Yes	CT	Yes	CT	CT
Thompson et al. (2009)	Yes*	Yes	Yes	Yes	Yes	CT	Yes
Verhoef et al. (2000)	No	CT	Yes	CT	CT	Yes(p)	Yes
Verhoef et al. (2005)	No	Yes	Yes	Yes	CT	Yes	CT
Wiegerink et al. (2008)	No	Yes	Yes	Yes	Yes	CT	CT
Wiegerink et al. (2010a)	No	Yes	Yes	Yes	Yes	CT	CT
Wiegerink et al. (2010b)	Yes*	Yes	Yes	Yes	Yes	Yes	Yes
Wiegerink et al. (2012)	Yes*	Yes	Yes	Yes	Yes	Yes	Yes
Zani et al. (1995)	No	Yes	Yes	Yes	Yes	CT	CT
<b>Mixed methods criteria</b>							
			Is there an adequate rationale for using mixed methods?	Are different components of study effectively integrated?	Are the outputs of integration adequately interpreted?	Are inconsistencies results addressed?	Are quality criteria adhered to?
Robertson et al. (2016)	Yes*	Yes	Yes	Yes	Yes	CT	CT

Key: Y=Yes, Y\*=Yes but not explicitly written as a research question, Yes(p)=Yes but partial, CT=Can't Tell.

Note: Please note that the Yes\* 'Yes but not explicitly written as a research question' and Yes(p) are not part of the MMAT response criteria but are additional responses provided by the reviewers for the purposes of transparency.

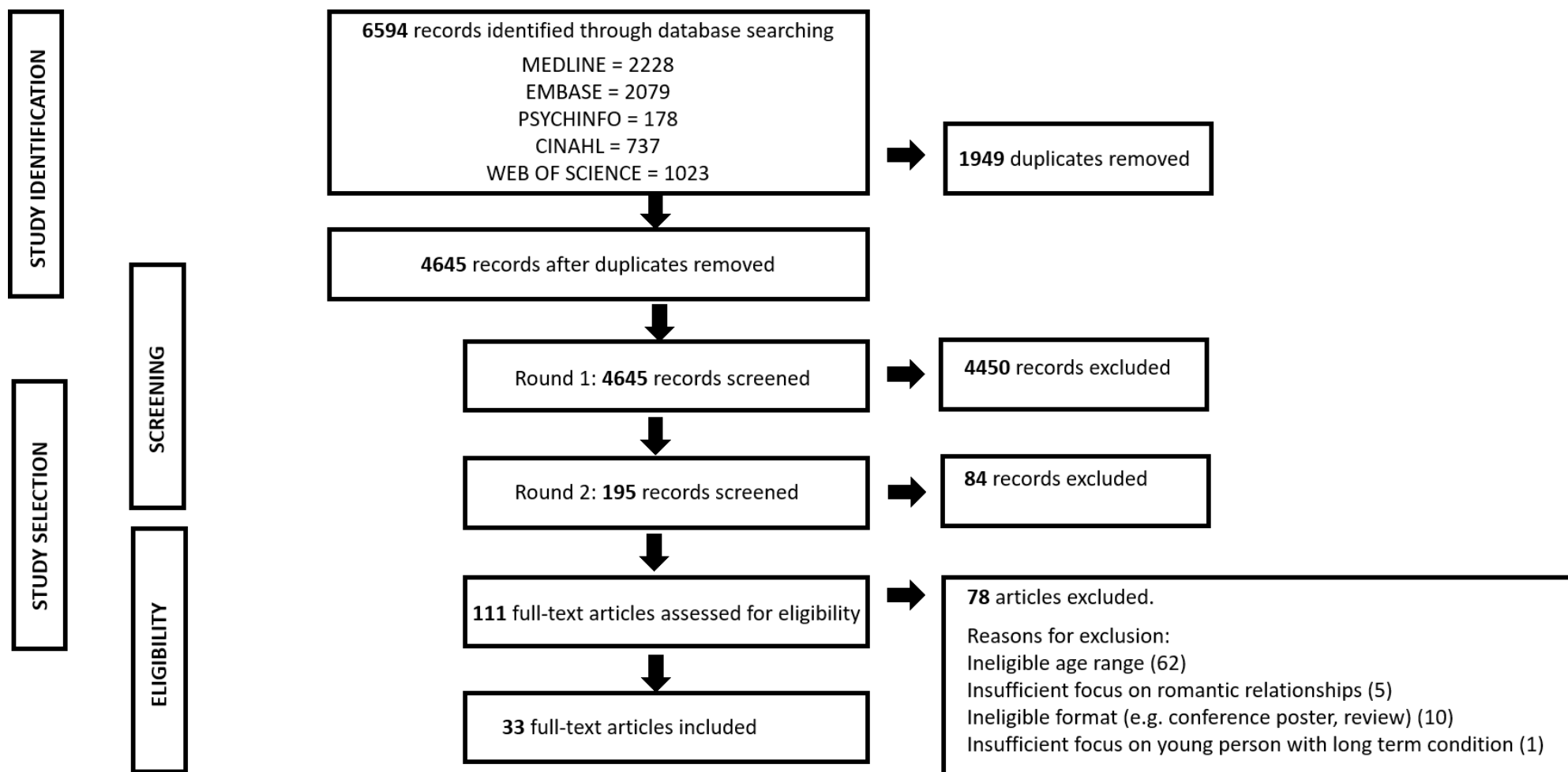
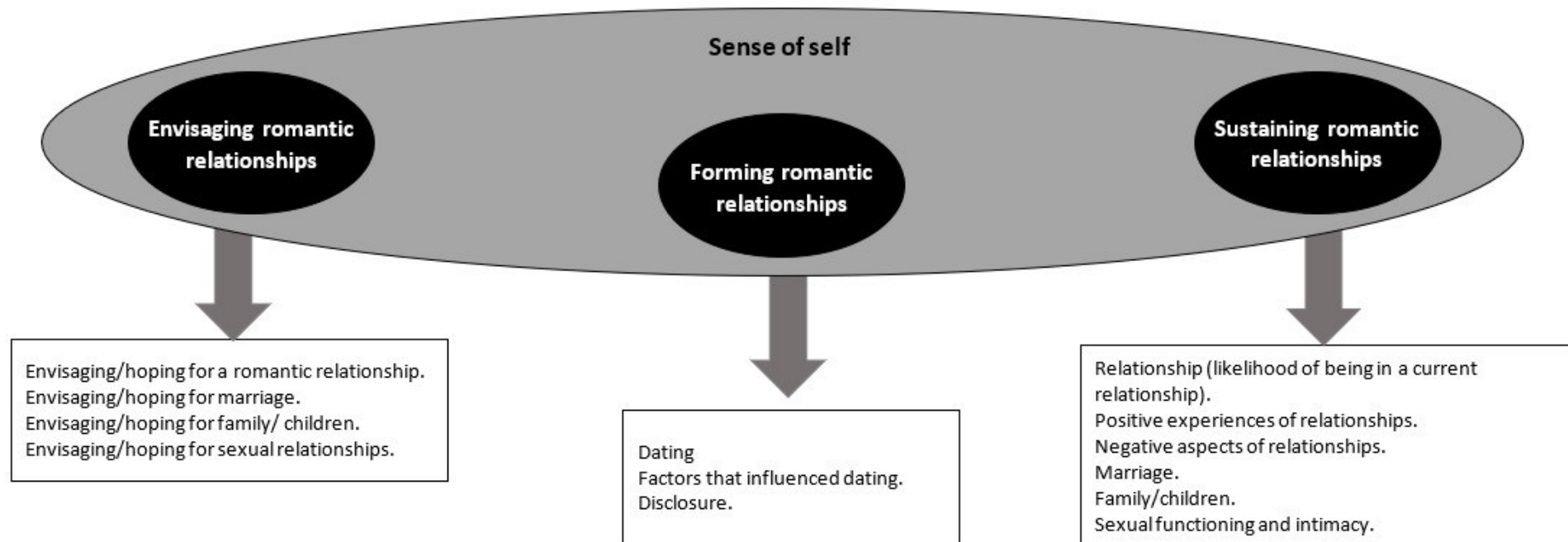


Figure 1: PRISMA flow chart of the scoping review search

Figure 2: Conceptualization of Thematic Results



These themes comprise envisaging romantic relationships, forming romantic relationships and sustaining romantic relationships, with each theme comprising smaller sub-themes. An overall thread (4) sense of self was interwoven throughout each of the three previously described themes.

**Supplementary Table 1: Full search terms for Ovid Medline (As An Example For The Other Databases)**

1. Chronic Pain/ or Chronic Disease/ or exp Diabetes Mellitus/ or Cystic Fibrosis/ or exp Epilepsy/ or exp Anemia, Sick Cell/ or Arthritis, Juvenile/ or Crohn Disease/ or Colitis, Ulcerative/ or Irritable Bowel Syndrome/ or Cerebral Palsy/ or exp Spinal Dysraphism/ or exp Musculoskeletal Diseases/ or Scoliosis/ or Fibromyalgia/ or exp Asthma/ or exp Heart Defects, Congenital/ or Ehlers-Danlos Syndrome/ or Hemophilia A/ or Complex Regional Pain Syndromes/ or exp Headache Disorders/ or Dysmenorrhea/ or Endometriosis/ or Reflex Sympathetic Dystrophy/ or Burns/

2. (((chronic or recurrent) adj2 pain?) or (Chronic adj2 disease?) or (Chronic adj2 condition?) or (chronic adj2 illness) or diabete? or (Cystic adj2 Fibrosis) or epilepsy or (sickle adj1 cell) or (Juvenile adj1 Rheumatoid adj1 Arthritis) or (Crohn? adj1 disease?) or (Ulcerative adj1 colitis) or (Irritable adj1 Bowel?) or (cerebral adj1 palsy) or (spina adj1 bifida) or (musculoskeletal? adj1 (condition? or disease? or malformation?)) or scoliosis or (juvenile adj1 fibromyalgia) or Asthma or (congenital adj2 heart adj2 (disease? or defect? or condition?)) or (Ehlers adj1 Danlos adj1 Syndrome) or H?emophilia or (Complex adj1 Regional adj1 Pain adj1 Syndrome?) or ((chronic or recurrent or disorder?) adj2 (headache? or migraine?)) or ((chronic or recurrent) adj2 abdominal pain?) or ((chronic or recurrent) adj2 (back pain or backache?)) or dysmenorrhea or endometriosis or Reflex Sympathetic Dystrophy or burns or burned).ti,ab,kw.

3. exp Neoplasms/

4. (neoplasm? or tumo?r? or cancer? or carcinoma?).ti,ab,kw.

5. 1 or 2 or 3 or 4

6. adolescent/ or Young Adult/

7. (teen? or teenager? or adolescen\* or youth? or ((young or emerging) adj2 adult\*)).ti,ab,kw.

8. 6 or 7

9. courtship/ or Marriage/ or Spouses/ or Sexual Partners/ or love/

10. (courtship or Marriage or romance or (Sexual adj2 Partner?) or boyfriend? or girlfriend?  
or attractiveness or (physical\* adj2 attract\*) or love or significant other? or dating).ti,ab,kw.

11. ((married or spous\* or romantic or LGBT or gay? or same sex or heterosexual? or  
homosexual? or lesbian? or sexual) adj3 relation\*).ti,ab,kw.

12. 9 or 10 or 11

13. 5 and 8 and 12

14. limit 13 to english

15. exp animals/ not humans/

16. 14 not 15

17. (addresses or autobiography or bibliography or biography or clinical conference or  
comment or congresses or consensus development conference or consensus development  
conference, nih or dataset or dictionary or directory or duplicate publication or editorial or  
government publications or guideline or interactive tutorial or lectures or legal cases or  
legislation or letter or meta analysis or news or newspaper article or patient education  
handout or periodical index or practice guideline or "review" or "scientific integrity review"  
or systematic reviews or technical report or video-audio media or webcasts).pt.

18. 16 not 17

## **Supplementary Table 2: Full Search Terms For Google Scholar**

adolescent|youth|teen|"young adult"|"young person"|juvenile chronic|headache|"abdominal  
pain"|arthritis|CRPS|"inflammatory bowel"|fibromyalgia|"sickle cell"|cancer|diabetes  
Romantic|courtship|marriage|"sexual relationship"|significant other



Supplementary Table 3: Key Data About the N=33 Eligible Studies

Author, Year of publication, Country.	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
Behle & Pinquart (2015) Germany	Do adolescents with & without physical difficulties (PD) differ in their perceived attainment of developmental tasks & does this vary by severity of PD?	<b>Design:</b> Quantitative non- randomized, cross sectional; 1 time point. Survey.  <b>Term:</b> Romantic relationship.	Adolescents with PD recruited from special schools for students with disabilities & comparison group of students recruited from regular schools.	<b>YPwLTC-P:</b> N=183; 104 male, 79 female. Mean age: 15.87, SD = 2.69.  <b>Other participant:</b> Peer without physical disability. N=320; 149 males, 171 females. Mean age 14.09, SD 1.89.	<b>LTC-P:</b> Neurological disabilities (41.5%), spina bifida (8.7%), muscular disabilities (10.9%), orthopaedic conditions (20.7%), other physical limitations (18%).		Young people with PD perceived themselves as just as successful at forming romantic relationships as their peers but less successful in being a member in a peer group (67% PD vs. 83% controls).	<b>Impact on relationship:</b> Higher levels of physical restrictions resulting from their PD were associated with significantly lower perceived attainment of romantic relationships.

Author,	Study aim/ Year of publication, Country.	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
Bellizzi et al. (2012), USA	Identify negative & positive impacts of cancer on developmental aspects of adolescence/young adulthood.	<b>Design:</b> Quantitative descriptive; 1 time point. Survey.  <b>Term:</b> Spouse/significant other.	AYA cancer patients were selected from 7 SEER (The Surveillance, Epidemiology, & End Results) cancer registries.	<b>YPwLTC-P:</b> N= 293 AYA representing 56% of total SEER registry of individuals aged 15-39 at time of diagnosis.  15-20yrs n=83 (15.9%),  <b>Other participant:</b>  Mean age 14.09, SD 1.89.	<b>LTC-P:</b> Cancer; germ cell cancer (39%), Hodgkin lymphoma (27.2%), non-Hodgkin lymphoma (25%), sarcoma (4.8%), acute lymphocytic leukaemia (4%).  <b>Duration:</b> not reported.	<b>Other details:</b> Single/ never married (n=273), married/living as married (n=219), divorced/separated (n=30).  Note that data in this cell refers to the entire sample of 15-39 year olds as not split by age for relationship status,	<b>Positive challenges:</b> 61% of 15-20-year olds reported positive changes in relationship with significant other.  <b>Impact on relationship:</b> Negative impact of cancer on relationship with significant other: 15-20 yrs (24.4%).  Negative impact on sexual function/intimate relationships.	

Author, Year of publication, Country.	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
Blum et al. (1991), USA	Identify patterns of peer & family relationships that are of primary concern for adolescents with spina bifida & cerebral palsy.	<b>Design:</b> Qualitative, descriptive; 1 time point. Interview & survey.  <b>Term:</b> Heterosexual relationship. Girlfriend/ boyfriend.	Recruited participants with spina bifida by purposive sampling and participants with cerebral palsy via public schools & regional summer camps for youths with disability.	<b>YPwLTC-P:</b> N=162. Reported even split between gender based on health condition. Age range: 12-22yrs.	<b>LTC-P:</b> Spina bifida (n=102), cerebral palsy (n=60).  <b>Duration:</b> not reported (assumed from birth).		Adolescents with SB & CP reported having friends that dated (44% & 54.2% respectively) but only 14.7% (SB) & 28.3% (CP) themselves had ever been on a date. 2/3rds of the participants had aspirations of marriage.	<b>Other details:</b> A very low proportion of those with spina bifida (17%) and cerebral palsy (12%) reported ever receiving any specific information relating to their condition & sexuality. 63.7% & 76.7%, respectively, indicated that they had thought about having children. Reasons for not wanting children were related to physical illness (e.g. cannot get pregnant, no one would want to marry me, having a child with a disability) except for a few stating they don't enjoy children.

Author, Year of publication, Country.	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
Bussing & Aro (1996) Finland	Explore the effect of chronic health conditions in adolescence on eventual transitional paths & young adult functioning.	<b>Design:</b>  Quantitative non- randomized, longitudinal cohort study; 2 time points (at 16 & 22 yrs old).  Survey.  <b>Term:</b> Significant other, steady partner.	Original study; all 9th grade students attending secondary school in one town.	YPwLTC-P: N=423; 283 female, 185 male. Age: 16yrs in Phase 1, 22yrs in Phase 2.  <b>Other participants:</b> Peer within same population N=779; 392 male, 387 female. Aged 16 in Phase 1, 22 in Phase 2.	LTC-P: Allergic conditions (75%), other conditions (25%) (e.g. diabetes mellitus, asthma, migraine headaches, non- allergic skin diseases). N=53, 25 males, 28 females has a 'serious' condition (e.g. asthma, renal disease, diabetes, seizure disorder).  <b>Duration:</b> not reported.	<b>Other details:</b>  Married/living with steady partner: with a condition (34.9%); without condition (26%). Not dating: with a condition (50.4%); without a condition (51%).	Women with chronic conditions more likely to be already married/live with a steady partner than similar peers (43.9% vs 34.3%). No significant differences in dating or early parenthood.	<b>Negative challenges:</b> Chronic conditions associated with slightly increased conflict with significant other (p = .03)

Author,	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
Calsbeek et al. (2002), Netherlands	Investigate the consequences of having a chronic digestive disorder on the social position of adolescents.	<b>Design:</b> Quantitative, non- randomised; 1 time point. Survey.  <b>Term:</b> Partnership.	Patients recruited via medical specialist at 11 academic & specialised hospitals & via a patient organisation. Healthy controls recruited randomly from files of GP's of participating patients.	<b>YPwLTC-P:</b> N=758; 362 male, 432 female. Age: 12-22yrs. Mean age 17.5-20yrs  <b>Other participants:</b> Peer within same population without chronic condition. N=306; 138 male, 168 female. Age 12-25yrs. Mean age 18.5yrs.	<b>LTC-P:</b> Inflammatory Bowel Disease (IBD)(n=305), chronic liver disease (CLD) (n=94), congenital digestive disorder (CDD) (n=137), coeliac disease (CD) (n=94), food allergy (FA) (n=98).  <b>Duration:</b> illness duration at least 6 months.	<b>Other details:</b> With a partner: IBD (49.1%), CLD (42.2%), CDD (40.8%), CD (56.7%), FA (55.4%), control (53.3%)	More adolescents with CDD feel restrictions making love (i.e. feeling ashamed). Those with CLD & FA significantly less confidence in "making a pass at someone".	

Author,	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
Canada et al. (2007), USA.	Develop & test an intervention designed to enhance psychosexual development in adolescents and young adults with cancer.	<b>Design:</b> Quantitative, pilot RCT; 3 time points (baseline, post- treatment and 3- month follow-up).  <b>Term:</b> Dating.	Recruited through registries from a Cancer Centre Adolescent & Young Adult Cancer Programme and a children's cancer centre.	<b>YPwLTC-P:</b> N=21, 9 male, 12 female. Mean age: waiting list 20.9yrs; intervention 21.8yrs. Waitlist completed the intervention after the 3-month time point.	<b>LTC-P:</b> Cancer: haematologic tumour (81.8% waiting list, 60.0% intervention); solid tumour (18.2% waiting list, 40.0% intervention).  <b>Duration:</b> 1-78 months since diagnosis; average 27.4 months	<b>Other details:</b> One ppt was married. No other info about relationship status of ppts.	<b>Other details:</b> From baseline to post intervention the intervention group reported significantly better cancer related sexual knowledge, improved perception of body competence, less dissatisfaction with particular body parts, decreased concerns about expressing affection, feeling attractive to the opposite sex & sexual concerns.	

Author,	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
Dorner (1976), UK	Answer how adolescents with Spina Bifida "feel about their situation".	<b>Design:</b> Quantitative descriptive; 1 time point. Survey.	Recruitment methods not stated. Although noted participants with SB & their families were part of a previous family based study (Dorner, 1975).	<b>YPwLTC-P:</b> N=46, 21 male, 25 female. Age range: 13-19yrs, mean 16.4yrs.	<b>LTC-P:</b> Spina bifida. <b>Duration:</b> not reported (assumed from birth).	<b>Other details:</b> 6 adolescents currently had a boyfriend or girlfriend.	<b>Negative challenges:</b> One boy with a girlfriend had urinary diversions and was anxious about how to tell his girlfriend (previous rejection). Other male participants with urinary appliances confirmed this concern in relations to the opposite sex.  <b>Impact on relationship:</b> Those with urinary diversions anxious about communicating. Those attending boarding schools for disabled perceived restrictions on communicating & socialising with romantic partners of the opposite gender.  <b>Other details:</b> Few patients had been able to establish relationships with the opposite sex. Had a heterosexual relationship: no (n=33), yes (n=13).- At time of interview 6 had a girlfriend or boyfriend. 30/46 thought they would be able to marry & wanted to do so;	

Author, Year of publication, Country.	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
								5 reported doubts but envisaged marriage. As many boys as girls envisaged marriage but girls were much more preoccupied with this than boys.
Domer (1977), UK	Explore the psychological & social problems for families with an adolescent with spina bifida.	<b>Design:</b> Qualitative; Potential 1 time point	participants identified from records at paediatric hospital.	<b>YPwLTC-P:</b> N=63; 28 male, 35 female. Age range: 13-19yrs, mean 16.4yrs.  <b>Other participants:</b> Parent ("mainly mothers") of young person with spina bifida. N=63 families.	<b>LTC-P:</b> Spina bifida.	<b>Other details:</b> 7 teenagers were "going out" with someone of the opposite sex.	N/A	<b>Negative challenges:</b> Three boys with girlfriends were inhibited to tell their girlfriend about condition for fear of rejection. Half of the 46 teenagers interviewed on their own described some degree of worry with thoughts about the opposite sex & half were "worried to a marked degree". Disease specific worries included: communicating about incontinence. Such worries were more likely to occur in older adolescents (reported by 17/25 teens aged 16years> & 6/21 <16years). Neither



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				Parent age range: not reported.				sex nor severity of condition was associated with worry.  <b>Other details:</b> No one who wished to marry wished to marry another disabled person. Parents & schools were the main sources of sex education (as reported by parents); only 15% learnt about sex from peers. Only 7/63 had a boyfriend/girlfriend; 80% were interested in the opposite sex. 4 girls had boyfriends & all 4 were engaged; their boyfriends were able bodied. Parents of 28 children expected child to marry; only 2 did not express worry about this expectation.

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Feragen et al. (2016), Norway	Explore the prevalence of romantic experiences among adolescents with a cleft lip &/or palate & investigate how these experiences could also be related to depressive symptoms & global self-worth.	<b>Design:</b> Quantitative non- randomized, cross sectional; 1 time point. Survey. <b>Term:</b> Romantic relationship.	Case records of 16 year olds born with cleft lip/palate from routine clinical assessments. C omparison group via a "Young in Norway" (national, representative survey).	YPwLTC-P: N=661; 398 male, 263 female. Age: 16yrs. <b>Other participants:</b> Within same population without cleft lip/palate N=1832; 944 male, 888 female. Age: 16yrs.	LTC-P: Cleft lip/palate (CL/P). <b>Duration:</b> since birth.		Males & females with visible/nonvisible CL/P both significantly less likely to be in a romantic relationship than comparison group or to have ever had a romantic relationship. Females with an additional non-specified condition (as well as CL/P) reported even fewer romantic relationships although same not found for males. Males & females CL/P had fewer romantic relationship experiences	<b>Other details:</b> Self-perceived romantic appeal was not significantly impacted by satisfaction with facial features directly affected by CL/P. Self-perceptions of social acceptance impacted on self-perceived romantic appeal; however, perceptions of close friendships did not influence self-perceived romantic appeal but they were significantly associated.

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							despite no differences in their self reported appeal	
Gerhardt et al. (2007), USA	Examine social & romantic outcomes among survivors of childhood cancer & comparison peers during the transition from adolescence to	<b>Design:</b> Quantitative, non- randomised, longitudinal survey; 2 time points (8- 14yrs, then 18- 22yrs). Only	Part of longitudinal study of children with cancer initially recruited from clinic rosters at	<b>YPwLTC-P:</b> N= 56; 39 male, 17 female. Average age: 18.65yrs.  <b>Other participants:</b> Family of young person. Classmate of survivor (matched	<b>LTC-P:</b> Cancer: lymphoma (39%), leukaemia (37%), solid tumors (24%).  <b>Duration:</b> mean years since diagnosis, 7.29 yrs.	<b>Other details:</b> Steady boyfriend/girlfriend: survivors (46%), comparison peers (48%). Few participants married: survivors (5%),	Trend (p = .05) for survivors to report lower scores of "romantic self concept" than comparison peers. Proportion of survivors reporting have a significant other was similar as was frequency of dating.  Very few in either group were married or had children	<b>Impact on relationship:</b> Greater initial treatment intensity associated with having future plans of marriage.

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	emerging adulthood.	follow-up reported in paper.  <b>Term:</b> Steady boyfriend/girlfriend.	a Children's hospital.	participant) and their family. N=60, 38 male, 22 female. Average age of youth: 18.64yrs. In cancer survivor group: average age father 47.67yrs, mother 45.4yrs. In comparison group: average age father 47.41, mother 45.03yrs, youth 18.64yrs.		comparison peers (3%).	& there were no differences in aspirations for marriage & children.	

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Gerhardt et al. (2011), USA	Understand the long-term impact of JIA on young adults, examining the social outcomes of youth treated for JIA & demographically similar peers.	<b>Design:</b> Quantitative non-randomised, longitudinal; 2 time points. Survey. Only follow-up reported in paper.  <b>Term:</b> Romantic relationship, steady partner.	Part of a longitudinal study of children with JIA initially recruited from clinic rosters at a large children's hospital.	<b>YPwLTC-P:</b> N=45; 12 male, 33 female. Age: at recruitment 8-14yrs, at follow-up 18-21 years; average age at follow-up 18.74yrs.  <b>Other participant:</b> Parents, peers. N=70, 31 female (peer group) Age: classmates, 18-21yrs, average 18.74yrs	<b>LTC-P:</b> Juvenile idiopathic arthritis (JIA).  <b>Duration:</b> mean since diagnosis 12.64yrs.	<b>Other details:</b> Steady boyfriend/girlfriend: JIA (44%), comparison peers (43%). Few participants married/engaged survivors (2%), comparison peers (2%).	Both groups described having similar levels of popularity, dating & having a steady partner. No difference between groups in the proportion who noted a desire to marry. However, trend for youth with JIA to report less frequently that having children was a long-term goal.	

Author, Year of publication, Country.	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
Helgeson et al. (2014a), USA	Examine whether friendship & romantic relationships of emerging adults with T1 diabetes differed from comparison group.	<b>Design:</b> Quantitative, non- randomized, longitudinal; 3 time points. Survey.  <b>Term:</b> Romantic relationship, romantic partner.	Participants recruited from an earlier study on adjustment to adolescence.	<b>YPwLTC-P:</b> N=118; 55 male, 63 female. Average age: 18yrs (age range not provided).  <b>Other participants:</b> Healthy adolescent within same population without Type 1 Diabetes. N=122; 57 male, 65 female. Average age: 18yrs.	<b>LTC-P:</b> Type 1 Diabetes. <b>Duration:</b> mean since diagnosis 11.04yrs.	<b>Other details:</b> In romantic relationship: 20% of participants (both groups) at all three waves of assessment.	Emerging adults with & without diabetes did not differ substantially in the amount of conflict with romantic partners. At T3 females with diabetes reported significantly less romantic support than counterparts; males with diabetes were not distinct from their peers.	<b>Negative challenges:</b> Romantic support was associated with increased distress & higher levels of disturbed eating behaviour for those with diabetes. Those with diabetes don't appear to gain the same benefits from romantic relationships as their control counterparts. Conflict with partner was associated with increased disordered eating for those with diabetes but not controls.

Author, Year of publication, Country.	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
Helgeson et al. (2014b), USA	Determine whether resilience, defined by cognitive adaption theory, predicted emerging adulthood outcomes among youth with & without type 1 diabetes.	<b>Design:</b> Quantitative, non- randomized; 3 time points. Survey.  <b>Term:</b> Romantic relationship.	Participants recruited from a previous longitudinal study on the transition through adolescence.	<b>YPwLTC-P:</b> N=118; 55 male, 63 female. Average age: 18yrs.  <b>Other participants:</b> Healthy adolescent within same population without Type 1 Diabetes. N=122; 57 male, 65 female. Average age: 18yrs.	<b>LTC-P:</b> Type 1 Diabetes.		Emerging adults with diabetes scored lower on the CAT index generally compared with controls.	<b>Other details:</b> At T2 women who scored high on the CAT index were more likely to be in a romantic relationship. At T3, the CAT index predicted being in a romantic relationship for the overall sample.

Author,	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
Heller et al. (2016), Canada	Explore how young people with spina bifida think about & discuss sexuality with their sexual & romantic partners in the context of their disability.	<b>Design:</b> Qualitative phenomenological; 1 time point. Interview.  <b>Term:</b> Sexual relationship, romantic relationship, romantic partner.	Purposive sample recruited from a large pediatric rehabilitation centre and the membership of a large provincial Spina Bifida and Hydrocephalus Association (SBHAO) in Canada.	<b>YPwLTC-P:</b> N=11; male 2, female 8, transgender male 1. Age:16-24yrs, mean 19.9yrs.	<b>LTC-P:</b> Spina bifida. <b>Duration:</b> not reported (assumed from birth)	<b>Other details:</b> In a romantic relationship: n=8, (n=6 sexual). Not in a relationship: n=3.  Sexual orientation reported: heterosexual (n=8), homosexual (n=2), bisexual (n=1).	<b>Negative challenges:</b> Young people reported feeling intense worry around how & when to disclose their condition to partners & the impact it may have on their sexual/romantic relationships. Worries revealed about timing of disclosure, rejection and lack of preparation about discussing sexuality and spina bifida.  <b>Positive challenges:</b> Reported difficulties in disclosing condition & its impacts to a partner, some who did disclose condition to partner gained confidence in themselves & relationship.  <b>Value/meaning of relationship:</b> Part of just being treated as if 'normal'.  <b>Impact on relationship:</b> Participants reported struggling to integrate disability & sexuality affecting perceived ability to lead a "typical" sex life. Some	



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								<p>participants had increased anxiety around being rejected because of incontinence/ disability.</p> <p><b>Other details:</b> Participants reported receiving limited sexual health education in school, but did receive some general sex education from parents, online resources, HCPs.</p>
Hullmann et al. (2012), USA	Examine dating anxiety & problems in social relationships & HRQoL in adolescents & young adults (AYA) with food	<p><b>Design:</b> Quantitative, non-randomized; 1 time point. Survey.</p> <p><b>Term:</b> Dating relationship, dating.</p>	Recruited through an online undergraduate participant pool at a large university.	<p><b>YPwLTC-P:</b> N=41; 9 male, 32 female. Age range: 18-24yrs, mean 19.56yrs.</p> <p><b>Other participants:</b> Healthy adolescent within same</p>	<p><b>LTC-P:</b> Food allergy.</p> <p><b>Duration:</b> not reported.</p>	<p><b>Other details:</b> In a current dating relationship: food allergies (51.2%); healthy (58.5%).</p>	<p>More participants reported being in a current dating relationship; FA (51.2%); healthy (58.5%). Most reported engaging in sexual intercourse with their current partner; FA (85.7%); healthy (100%). Those with FA</p>	<p><b>Impact on relationship:</b> Most participants, 85.7% of participants reported that their allergies have actually interfered with having sexual intercourse with their current partner.</p>

Author, Year of publication, Country.	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
	allergies compared with their healthy peers.			population without food allergy. N=41, 9 male, 32 female. Age range: 18-24yrs, mean 19.49yrs.			reported experiencing greater dating anxiety & experienced greater fear of negative evaluation than healthy individuals.	
Martins et al. (2018), UK	Explore the sexual health information/ support needs of adolescents & young adults with cancer.	<b>Design:</b> Qualitative; Established 1 time point. Workshop (activities & focus group). <b>Term:</b> Sexual relationship, relationships	Established members of a patient user group - the BRIGHTLIGH T Young Advisory Panel (YAP).	<b>YPwLTC-P:</b> N=5; 2 male, 3 female (included gay & straight). Age range: 16-24yrs.	<b>LTC-P:</b> Cancer: haematological (n=3), solid tumour (n=2). <b>Duration:</b> diagnosed when aged 13-22yrs.		<b>Negative challenges:</b> Young people may also miss out on discussions with their peers - due to isolation from peers - about romantic & sexual relationships.  <b>Impact on relationship:</b> Sexual desire influenced by treatment side-effects (e.g., baldness, scars, mouth sores). The way young people felt about their bodies, energy levels & sexual desire impacted development of sexual relationships & intimacy.	

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								<b>Other details:</b> Lack of discussions with HCPs about impact of treatment on sex/risks of infection negatively impacted on romantic/sexual relationship. Some felt embarrassed to ask questions, did not have enough time in consultations to discuss sex/relationships. Young people reported HCP's uncomfortable to discuss sex & intimacy-related information with them. Parents' role pivotal; need to balance privacy & parental support. Young people wanted ongoing access to information, even when treatment ends.

Author,	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
Robertson et al. (2016), Australia	Understand better how AYAs in early survivorship perceive the quality of their interpersonal relationships & sexual functioning/ satisfaction in reference to their cancer experience.	<b>Design:</b> Mixed methods; 1 time point. Interview & questionnaire.  <b>Term:</b> Sexual/ romantic relationship, interpersonal sexual relationship, partner.	Recruited from hospitals around Australia via mailed invitation packages.	<b>YPwLTC-P:</b> N= 43; 21 male, 22 female. Age range: 15-26yrs.	<b>LTC-P:</b> Cancer: solid, blood & brain cancers.  <b>Mean age at diagnosis:</b> 11-25yrs.	<b>Duration:</b> average relationship 19.3month; range 2- 36. Other details: in relationship (n=16); single (n=27).	<b>Negative challenges:</b> 8/16 individuals in a relationship reported relationship difficulties, 7/8 reported at least one slight difficulty & one reported slight to moderate difficulties across all areas. Most frequently reported difficulties were interpersonal conflicts due to sexual difficulties (6/8) & a loss of sexual interest (5/8). Three reported relationship conflict due to lack of communication.  <b>Positive challenges:</b> Young people with "supportive" & "understanding" partners appeared to have better communication & less conflict. Two partners reported that cancer was even beneficial for their relationship, strengthening it. AYA did not report relationship dissatisfaction in previous 30 days.	

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								<p><b>Value/meaning of relationship:</b> emotional support from their partner both during &amp; after treatment enabled 5/16 cope more positively with cancer experience.</p> <p><b>Impact on relationship:</b> Relationship conflict post treatment due to lack of sexual interest: (n=6). <b>Other details:</b> 8/16 reported no relationship difficulties or sexual difficulties.</p>
Sawin et al. (2006), USA	Examine whether differences exist between adolescents with spina bifida & their parents in the domains of	<p><b>Design:</b> Quantitative descriptive; 1 time point. Survey.</p> <p><b>Term:</b> Romantic appeal</p>	Convenience sample of adolescents with myelomeningo cele & their primary	<p><b>YPwLTC-P:</b> N=66; 28 male, 38 female. Age range: 12-21yrs, mean 16.2yrs.</p> <p><b>Other participants:</b> Primary caregiver (mothers &amp; fathers) of</p>	<p><b>LTC-P:</b> Myelomeningocele. <b>Duration:</b> not reported, assumed since birth.</p>			Adolescents' mean scores in perception of involvement in romantic relationships were significantly higher than parents' ratings.

Author,	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
	adolescent activities, beliefs & outcome competencies.		caregiver seen in a speciality clinic at paediatric hospital.	young person. Number: not reported. Age range: not reported.				
Secor- Turner et al. (2011), USA	Identify challenges that teens experience while living with juvenile arthritis (JA) from the perspective of youth & young adults with JA.	<b>Design:</b> Qualitative; 1 time point. Focus groups.  <b>Term:</b> Dating, partner	Recruited through the local chapter of the Arthritis Foundation & through pediatric rheumatology clinics.	<b>YPwLTC-P:</b> N=10; male 3, female 7. Age range: 14-28yrs	<b>LTC-P:</b> Juvenile arthritis. (1 participant had lupus with arthritis).  <b>Duration:</b> not reported.		<b>Negative challenges:</b> Young people (14-21yrs) did not identify dating challenges but noted challenges of other people not understanding arthritis & disclosing /explaining arthritis to friends.	

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Seiffge-Krenke (1997), Germany	Are chronically ill adolescents able to balance positive & negative aspects in their romantic relationships & if the quality of their romantic relationships equals the quality of those experience by health adolescents?	<b>Design:</b> Quantitative descriptive, longitudinal, 4 time points. Survey & interviews.  <b>Term:</b> Partner, boyfriend, girlfriend, romantic relationship, romantic partner.	Not reported.	<b>YPwLTC-P:</b> N=91, male 46, female 45. Mean age (healthy & diabetic): yr 1, 13.9yrs; yr 4, 17.1yrs.  <b>Other participants:</b> Healthy controls. N=107; male 46, female 61. Mean age (healthy & diabetic): yr 1, 13.9yrs; yr 4, 17.1yrs.	<b>LTC-P:</b> Diabetes mellitus. <b>Duration:</b> mean time (start of study) since diagnosis 5.4yrs.	<b>Other details:</b> In a relationship, Yr 1, diabetics (1%), healthy (4%); Yr2, diabetics (2%), healthy (14%); Yr3, diabetics (8%), healthy (22%); Yr4, diabetics (11%), healthy (36%).	Marked differences in formal characteristics & in perception of romantic relationships in adolescents as a function of health status. Diabetic adolescents (DA) started to have heterosexual relationships later than healthy adolescents (HA). DA were less sexually active than HA. Romantic relationships seemed to serve different functions in diabetic & healthy adolescents. Higher levels of intimacy reported by females,	

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							irrespective of health status  but increasing discrepancies  in intimacy in romantic relationships were perceived  by male & female DA.  Conflict/satisfaction in romantic relationships somewhat different.	
Sodergren et al. (2018), France, Israel, Norway, Poland,	Capture the HRQoL issues described by adolescents & young adults (AYAs) receiving treatment or	<b>Design:</b> Qualitative; 1 time point. Interview plus case report form.  <b>Term:</b> Romantic relationship, partner.	Recruited from AYAs (14-25 yrs) from 7 research centres across France, Israel, Norway,	YPwLTC-P: N=45; male 24, female 21. Age range: 14-25yrs, mean 20.3yrs.	LTC-P: Cancer: most frequent, leukaemia (26.7%); lymphoma (17.8%); gynaecological 11.1%  Note: 77.8% on treatment, 22.2% on	<b>Other details:</b> lived with partner (64%), lived with parents (24%).		<b>Negative challenges:</b> 91% reported social impact of cancer & treatment included effects on friendships, family & romantic relationships. Some AYAs reported having to surrender independence enjoyed by their peers. Difficulties in establishing new romantic relationships /dating due to limited opportunities, body image & self-esteem issues were also described.



Author,	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
Netherlands, UK	palliative care for cancer.		Poland, the Netherlands & UK.		supportive/palliative care.  <b>Duration:</b> Range (since diagnosis) 1 month-7yrs; median 9months.			<b>Impact on relationship:</b> some reported cancer/treatment put relationship with partners under strain. Limited opportunities for spending time with partners & for intimacy; sex life & plans to start a family had to be put on hold. Male & female AYAs considered the impact of treatment on their ability to have children.
Stinson et al. (2015), Canada	Gain insight into adolescents & parents' perspectives are related to issues of romantic relationships & sexual relationships	<b>Design:</b> Qualitative, Purposive phenomenological; 1 time point. Interview.  <b>Term:</b> Romantic relationship, dating, partner.	Purposive maximum variation sampling strategy via a large metropolitan tertiary	<b>YPwLTC-P:</b> N=20, male 9, female 11. Age range: 12- 17yrs, mean 15yrs.  <b>Other participants:</b> Parent. N=20; male 6, female 14. Age range: 30-59yrs.	<b>LTC-P:</b> Cancer (various): most frequent, acute lymphoblastic leukaemia (20%), osteosarcoma 15%.  <b>Duration:</b> Age at diagnosis 8-16 years.			<b>Negative challenges:</b> Adolescents expressed apprehension that cancer would impact on romantic relationships citing diminished self-esteem & other psychological impacts as reasons why relationships may be difficult.  <b>Value/meaning of relationship:</b> For many adolescents & parents, adolescent romantic relationships not a priority; entire focus on treatment. Those with

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	& fertility during/ after cancer treatment.		pediatric hematology/ oncology care centre.					<p>experience of romantic relationships, relationship/dating was a source of support.</p> <p><b>Impact of relationship:</b> Ability to engage with potential partners was limited by fatigue, nausea &amp; time spent receiving cancer care. Stigma of being ill was barrier to engaging with potential partners. Adolescents wanted to develop sexual relationships, no expectation that cancer would affect this.</p> <p><b>Other details:</b> Adolescents endorsed the need for access to high quality information about dating, sexuality &amp; fertility. Adolescents keen to receive information.</p>

Author, Year of publication, Country.	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
Thompson et al. (2009), USA	Assess whether childhood cancer survivors experience difficulties in their romantic relationships during emerging adulthood (18-25 years) & identify who may be at risk for long-term social sequelae.	<b>Design:</b> Quantitative descriptive; 1 time point. Survey.  <b>Term:</b> Relationship, Romantic relationship.	Recruited from the oncology database at a large children's hospital. Healthy controls recruited through survivors referrals of same sex peers between ages 18-25 & the university	<b>YPwLTC-P:</b> N=60, male 35.5%, female 64.5%. Age range: 18- 25yrs, mean 21.61yrs.  <b>Other participants:</b> Healthy control. N=60, male 35.5%, female 64.5%. Age range: 18-25yrs, mean 20.05yrs.	<b>LTC-P:</b> Cancer: leukaemia (n=22), lymphoma (n=12), solid tumour (n=26).  <b>Duration:</b> mean of 8.06yrs since diagnosis.	<b>Other details:</b> Ever had a relationship: survivors (89.5%), controls (92.3%). Ever been married: survivors (7.1%), controls (1.5%). Lived with partner: survivors (7.1%), controls (4.6%). In a relationship: survivors (52.6%), controls (70.8%). Average number of relationships in last 5	Survivors reported more distress at the end of relationship. No group differences were found for relationship satisfaction, average conflict or average duration. Survivors in the highest intensity group had significantly fewer relationships in the last 5 years than controls.	<b>Impact of relationship:</b> In survivor group higher treatment intensity related to lower relationship satisfaction. Older age at diagnosis & higher trait anxiety predicted lower levels of relationship satisfaction. Higher trait anxiety & more severe treatment predicted lower levels of relationship satisfaction.

Author, Year of publication, Country.	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
Thompson et al. (2013), USA	To explore the nature/perceptions of romantic relationships among emerging adult survivors of childhood cancer.	<b>Design:</b> Qualitative; 1 time point. Interview.  <b>Term:</b> Romantic relationship, partner.	Recruited in follow-up from a larger online, quantitative study of romantic relationships among	YPwLTC-P: N=18, all female. Age range 19-25yrs, mean 21.56yrs.	LTC-P: Cancer: leukaemia (n=5), lymphoma(n=3) ; solid tumour (n=10).  <b>Duration:</b> age at diagnosis range 2–15 yrs, mean 7.41 yrs	<b>Other details:</b> In romantic relationship (66.6%); 1 married, 1 divorced.		<b>Negative challenges:</b> Survivors reported challenges connecting with & forming close relationships with others including romantic partners. Feeling more mature/having different priorities than same-aged peers had the potential to both promote/challenge the development/maintenance of romantic partnerships. Half were willing to discuss the factual aspects of cancer history with romantic partners, other half more

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			emerging adult survivors of childhood cancer.					<p>reluctant/fearful of disclosing such “critical” information. Most described a more general difficulty/cautiousness with sharing personal thoughts/feelings with others.</p> <p><b>Positive challenges:</b> Priorities changed as result of cancer; life seen as short &amp; precious &amp; health &amp; families valued above all. Many survivors described this altered life perspective as impacting their relationships in a positive direction, e.g., not arguing or being bothered by petty things.</p> <p><b>Impact on relationship:</b> Reluctance to communicate intimate thoughts &amp; feelings, may result from covering- up negative emotions to prevent upsetting &amp; protect loved ones. Physical self-consciousness &amp; self- confidence impacted as a result of disease, treatment &amp;</p>

Author,	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
								treatment-related side effects. Negative body images identified as problematic in the formation of romantic relationships & development of intimacy. All but one of the participants reported significant worry about their ability to have children (& fears about the health of their future children).
								<b>Other details:</b> Number of relationships in the past 5 years: range (1-4), mean (2.33).
Verhoef et al. (2000), Netherlands	To provide information about sex education, relationships & sexual functioning of adolescents with spina bifida.	<b>Design:</b> Quantitative descriptive; 1 time point.  <b>Term:</b> Partner, relationship.	Recruited via outpatients of spina bifida teams.	YPwLTC-P: N=83; male 39, female 44.  Age range 16-25yrs.	LTC-P: Spina bifida (aperta & occulta):  <b>Duration:</b> not reported, assumed since birth.	<b>Other details:</b> Has partner (25%); previously had a partner (39%).		<b>Negative challenges:</b> 68% mentioned problems of getting involved in relationships. Obstacles included lack of self-confidence (52%), incontinence (41%), being treated differently (30%) & wheelchair dependency (27%). Lack of self-confidence (35%) & incontinence (36%) were important obstacles to sexual contacts.

Author, Year of publication, Country.	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
								<b>Other details:</b> Minority had received education specific to their condition.
Verhoef et al. (2005), Netherlands	To assess the adequacy of sex education & to determine the incidence of various difficulties encountered in relationships & sexual contact by young adults who	<b>Design:</b> Quantitative descriptive; 1 time point. <b>Term:</b> Partner, relationship.	Patients for the ASPINE study were recruited from specialised multidisciplinary care teams for spina bifida & via Dutch patient association,	<b>YPwLTC-P:</b> N=157. male 64, female 93. Age range 16-25yrs, mean 20.8yrs.	<b>LTC-P:</b> Spina bifida with & without hydrocephalus (HC).  <b>Duration:</b> not reported, assumed since birth.	<b>Other details:</b> Has partner (25%).		<b>Negative challenges:</b> Obstacles included lack of self-confidence (53%), incontinence (47% of incontinent patients), wheelchair dependency (55%). No significant gender differences found in obstacles to starting relationship. Of 93 SB patients who had indicated that they had ever had sexual contact, most frequently mentioned obstacles: incontinence & lack of self-confidence; no differences between young men & women.  <b>Impact on relationship:</b> Satisfaction with one's sex life was only related to HC, with patients without HC

Author, Year of publication, Country.	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
	have spina bifida in the Netherlands.		organisations for sheltered homes & rehabilitation centres.					being twice as likely to be satisfied with their present sex lives.  <b>Other details:</b> 25% had a partner, 29 had previously had a partner & 46% had never had a partner. 3/4 of patients not in a relationship expressed a wish to have a partner. Problems with sexuality relating to SB (e.g., handicap, fertility, heredity) rarely been discussed. 60% patients wished to have children in the future.
Wiegerink et al. (2008), Netherlands	To describe the social, intimate & sexual relationships of Dutch adolescents with cerebral palsy compared with	<b>Design:</b> Quantitative descriptive; 1 time point. Survey.  <b>Term:</b> Dating, Intimate relationships, sexual	Participants recruited from 8 regional rehabilitation centres & departments (part of a larger	<b>YPwLTC-P:</b> N=103, male 62, female 41. Age range 16-20yrs, mean 17.9yrs.  <b>Other participants:</b> On some measures ppts were compared	<b>LTC-P:</b> Cerebral palsy. <b>Duration:</b> not reported, assumed since birth.	<b>Other details:</b> Participants with CP with steady partner (19%). Males with CP steady girlfriend (11%); girls with CP	Usually had a date: CP (44%), age-mates (46%). Had steady partner: CP (19% more girls than boys), age- mates (46%). Those with CP had sig. less experience in dating & intimate	<b>Negative challenges:</b> Obstacles in starting a relationship: perceived lack of self-confidence (41%), being treated differently (23%) felt they were treated differently. Other perceived problems: physical disabilities (21%), wheelchair dependency for non- ambulators (11%). Boys & girls did not differ on obstacles reported.



Author, Year of publication, Country.	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
	their able-bodied age peers.	relationship, courtship, boyfriend, girlfriend.	CP Transition study).	with reference data available for able- bodied age-mates (Netherlands/USA).		with steady boyfriend (32%).	relationships than their age- mates. Girls (CP) relatively less experience with falling in love & courtship than age- mates; boys (CP) had a steady girlfriend. Aged 16-20 years those with CP less focused on sexuality & had both sig. less sexual experience than age mates.	<b>Impact on relationship:</b> Only 7% reported that their sexual enjoyment was influenced by their physical disability. 22 participants (26%) indicated they were not able to act sexually as they would like because of physical limitations. <b>Other details:</b> 91% of those with CP had been in love; 73% had experience with courtship. Only 14% had received specific information on disability & sexuality. Various dating skills reported: impress the other/use friend to make contact (76%), just get on with it (633%). CP evaluated their physical appearance similar to reference values. Dutch adolescents with CP had sig. higher sexual self-esteem, body esteem, & felt more attractive to others compared with persons with physical disabilities in western societies.

Author, Year of publication, Country.	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
Wiegerink et al. (2010a), Netherlands	Describe the development of romantic relationships & sexual activity of young adults with cerebral palsy and to compare with an age-appropriate Dutch reference population.	<b>Design:</b> Qualitative descriptive; 3 time points. Quantitative interview and measures.  <b>Term:</b> Romantic relationship, dating.	Participants recruited from 8 regional rehabilitation centres & departments (part of a larger CP Transition study).	<b>YPwLTC-P:</b> N=103, male 61, female 42. Age range (at T1): 16- 20yrs, mean 19.48yrs.  <b>Other participants:</b> Able-bodied, age- mates from age- appropriate, Dutch reference population. N=1803, male 912, female 901. Age range 20-24yrs.	<b>LTC-P:</b> Cerebral palsy. <b>Duration:</b> not reported, assumed since birth.		Fewer men and fewer women with CP in current relationships in comparison with gender-specific reference groups.	<b>Other details:</b> Largest increase in dating activity between T1 & T2. Between T1 & T3, no significant increase experience with romantic relationships or being in a romantic relationship. Young adults with lower education levels began dating later than those with higher education. No demographic or physical characteristics were associated with experience of romantic relationships. Sig. more women in current relationships than men.

Author, Year of publication, Country.	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
Wiegerink et al (2010b), Netherlands	Describe the peer group activities, romantic relationships, & sexual activity & their interrelations of young adults with cerebral palsy.	<b>Design:</b> Quantitative descriptive, cross- sectional; 1 time point. Questionnaire. <b>Term:</b> Dating, romantic relationship	Participants recruited from 8 regional rehabilitation centres & departments (part of a larger CP Transition study).	<b>YPwLTC-P:</b> N=87, male 51, female 26. Age range: 18-22yrs, mean 20.4yrs.  <b>Other participants:</b> Age-appropriate, Dutch reference population. N=1962. male 988, female 974. Age range: 18-22yrs.	<b>LTC-P:</b> Cerebral palsy. <b>Duration:</b> not reported, assumed since birth.		Significantly fewer participants had a current romantic relationship than the age-appropriate Dutch reference population. Participants had significantly less experience with sexual milestones than reference population.	<b>Other details:</b> Many participants had relatively active dating skills; no difference between men & women. Been on a date (71%), been in love once (94%), experienced a romantic relationship (77%), currently in a relationship (23%). Being older was associated with dating (& sexual) experience. Factors associated with more dating: having more friends (4x more dating experience), more participation in going out activities (associated with dating in males but not females). Factors associated with more romantic relationships: going out with friends (4x more likely) & contact with mixed gender peers & participating in sports.

Author, Year of publication, Country.	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
Wiegerink et al. (2012), Netherlands	Explore assumed determinants of romantic relationships & sexual activity of young adults with cerebral palsy.	<b>Design:</b> Quantitative descriptive, cross-sectional; 1 time point. Self-report survey, various scales.  <b>Term:</b> Romantic relationship.	Participants recruited from 8 regional rehabilitation centres & departments (part of a larger CP Transition study).	<b>YPwLTC-P:</b> N=74; male 46, female 28. Age range: 20-25yrs, mean 22.39yrs.  <b>Other participants:</b> Age-appropriate, Dutch reference population. N=196, male 21%, female 79%. Mean age: 20.5yrs.	<b>LTC-P:</b> Cerebral palsy. <b>Duration:</b> not reported, assumed since birth.	<b>Other details:</b> In a relationship, participants (26%), reference group (63%).	Experience of romantic relationship: CP (73%), reference group (91%).  Current relationship: CP (26%), ref pop. (63%).  Experience of French kissing: CP (78%), ref pop. (91%).  Experience with intercourse: CP (54%), ref. pop. (83%).  CP scored significantly higher on persistence than ref population.	<b>Other details:</b> More effort (feelings of competence), a higher self-esteem, & a positive sexual esteem were associated with a current romantic relationship. Positive associations with romantic relationships for regular secondary education & negative associations with a rejecting parenting style for a current romantic relationship.
Wilson et al. (2007), UK	Examine the experiences of young people living	<b>Design:</b> Qualitative Interpretive Phenomenological	Identified through a follow up	<b>YPwLTC-P:</b> N=16, male 11, female 5.	<b>LTC-P:</b> Bladder exstrophy. <b>Duration:</b>		Participants stated that sexual activity had begun at the same time as their peers.	<b>Negative challenges:</b> All participants reported concerns around sexual relationships & felt pressured to have an intimate partner so they would not be “left

Author, Year of publication, Country.	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
	with bladder exstrophy	Analysis; 1 time point. Interviews.  <b>Term:</b> Sexual relationship, intimate partner.	clinic at a teaching hospital.	Age range 16-21yrs, mean 19yrs.	not reported, assumed since birth.			<p>behind” their friends. Participants lacked confidence when talking to members of the opposite sex, as well as when to move toward greater physical intimacy. Fears prevented some participants from engaging in casual relationships because of difficulties trusting others &amp; fears of rejection. Struggles exacerbated by fears of rejection about disclosing about condition/consequences to sexual partners.</p> <p><b>Positive challenges:</b> Some had experience little control over disclosure &amp; for some this had unanticipated positive consequences such as better understanding and support.</p> <p><b>Impact on relationship:</b> Specific physical issues relating to the appearance and functionality of their genitals fuelled many of their anxieties surrounding</p>

Author, Year of publication, Country.	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
								entering into sexual relationships and worry about rejection.  <b>Other details:</b> All participants very positive in their hopes/expectations for future successful sexual relationships.
Zani et al. (1995), Italy	Evaluate the impact of chronic illness i.e. thalassemia major on the psychological functioning & social behaviour of adolescent patients.	<b>Design:</b> Quantitative descriptive; 1 time point. Survey.  <b>Term:</b> Relationship, partner.	Patients recruited via day hospital appointment.  Controls recruited from a local vocational institute.	<b>YPwLTC-P:</b> N=90, male 45, 45 female. Age range: 14-22yrs, mean 17.8yrs.  <b>Other participants:</b> Healthy control group. N=100: male 43, female 57. Age	<b>LTC-P:</b> Thalassaemia. <b>Duration:</b> not reported.	<b>Other details:</b> In a relationship, thalassaemic (43.3%), controls (53.3%).	Had a partner: Thalassaemic (43.3%), control (53.5%). Both groups considered it "very important" to have a girlfriend/boyfriend & thought similar characteristics were important in a relationship. Hoping relationship would last & idea of being married	

Author,	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
				range: 14-22yrs, mean 17.9yrs.			more important for thalassaemic than controls. Both thalassaemic & controls considered it important to get married & have children.	
Zukerman et al. (2011), USA	Examine the predictive utility of demographic, individual, & family-based factors during adolescence on	<b>Design:</b> Quantitative non- randomized; 3 time points. Survey & observation.  <b>Term:</b> Romantic relationship.	Patients/familie s recruited from three hospitals & a state-wide SB association. Controls	<b>YPwLTC-P:</b> N=52 (T6), male 28, female 24. Age: T1, 8-9yrs; T4, 14-15yrs; T6 , 18-19yrs. This study comprised three timepoints only within	<b>LTC:</b> Spina bifida.  <b>Duration:</b> not reported, assumed since birth.	<b>Other details:</b> In a relationship at T6, SB (59%), controls (68%).	Typically developing youth were 4.24 times more likely to have had romantic relationship experience (significant) & 1.48 times more likely to currently be in a romantic relationship (non-	

Author, Year of publication, Country.	Study aim/ question	Research Design, Terms used to describe relationships.	Participant recruitment	Young person with Long-term physical health condition (YPwLTC-P) & Other participants (including controls): Number by gender, Age range/ mean age.	Long-term physical health condition (LTC-P) details, Duration of condition	Other details (e.g., dating, in relationship, married)	Findings related to comparison with healthy peers	Negative challenges and positive challenges associated with relationships, Value/meaning of relationship, Impact of long-term physical health condition on relationship (as reported by young people), Other details.
	achievement of emerging adulthood milestones in youth with & without spina bifida (SB).		recruited from schools where participating children with SB enrolled. (Part of a larger longitudinal study).	a larger six timepoint study.  <b>Other participant:</b> Parents (mostly mothers) of SB child & comparison families matched on key demographic variables. N=60 healthy peers, male 32, female 28.			significant) than youth with SB. Among youth who completed high school, youth with SB were less likely to have ever had a romantic relationship compared to typically developing youth.  Emerging adults with & without SB reported a similar number of close friends.	



**Supplementary Table 4: Relationship Characteristics of Individual Studies**

<b>Relationship category</b>	<b>Study name and year</b>	<b>Percentages of individuals with Long-Term Physical Health Conditions (LTC-P) engaging/having engaged with different types of romantic relationships including similar percentages for comparison group(s) where provided</b>	<b>Comparison of Long-Term Physical Health Condition (LTC-P) group with normative comparison group with regard to relationship characteristics</b>
Dating	Bussing & Aro (1996)	50.40% of 22 year olds with an ongoing LTC-P (n=423) reported currently dating compared with 51.00% without a condition (n=779).	A similar number of individuals in the comparison group reported currently dating compared with those with LTC-P.
	Dorner (1976)	29.26% of individuals with spina bifida (SB) (13-19 years) (n=46) reported ever having a boyfriend or girlfriend, with 13.04% (n=6) reporting a current boyfriend or girlfriend.	No comparison group.
	Dorner (1977)	11.11% of individuals with SB (13-19 years) (n=7) reported currently 'going out' with someone of the opposite sex.	No comparison group.
	Hullmann et al. (2012)	51.20% of individuals with food allergies (18-24 years) (n=41) and 58.50% of comparison group (n=41) reported currently being in a dating relationship.	A greater number of individuals in the comparison group reported currently dating relationship compared with those with LTC-P.
In a relationship	Heller et al. (2016)	72.70% of individuals with SB (16-25 years) (n=11) reported currently being in a relationship. Of whole sample, 72.70% reported being heterosexual, 18.18% homosexual and 9.09% bisexual.	No comparison group.
	Robertson et al. (2016)	37.20% of individuals post cancer treatment (16-26 years) (n=43) reported currently being in a relationship. Average relationship duration was 19.3 months. 50.00% of individuals reported minor relationship/sexual difficulties.	No comparison group.
	Seiffge-Krenke (1997)	Relationship status for individuals with Type 1 Diabetes (T1DM) (n=91) and a comparison group (n=107) is described across four consecutive years (individuals aged 13.9 years at year one timepoint). Reports of being in a relationship Year 1: 1.00% T1DM vs 4% comparison group. Year 2: 2.00% T1DM vs 14% comparison). Year 3: 8.00% T1DM vs 22.00% comparison. Year 4: 11.00% T1DM vs 36.00% comparison).	A similar number of individuals in the comparison group reported being in a relationship at each of the four timepoints compared with those with LTC-P.

<b>Relationship category</b>	<b>Study name and year</b>	<b>Percentages of individuals with Long-Term Physical Health Conditions (LTC-P) engaging/having engaged with different types of romantic relationships including similar percentages for comparison group(s) where provided</b>	<b>Comparison of Long-Term Physical Health Condition (LTC-P) group with normative comparison group with regard to relationship characteristics</b>
In a partnership	Thompson et al. (2009)	89.50% of individuals (18-25 years) post cancer diagnosis (survivors) (n=60) reported ever having a relationship vs 92.30% of those in comparison group (n=60). Average number of relationships (past five years): survivors was 1.77 survivors vs 2.29 comparison group.	A similar number of individuals in comparison group reported ever having a relationship and had a larger number of relationships compared with those with LTC-P.
	Thompson et al. (2013)	66.66% of individuals (18-25 years) post cancer diagnosis (survivors) (n=18) reported currently being in a romantic relationship.	No comparison group.
	Wiegerink et al. (2012)	26.00% of individuals with cerebral palsy (CP) (20-25 years) (n=74) reported currently being in a relationship vs 63.00% in comparison group (n=196). 73.00% CP reported ever having experienced a romantic relationship vs 91.00% in comparison group. .	A greater number of individuals in the comparison group reported currently being in a relationship and/or ever having had a romantic relationship compared with those with LTC-P.
	Zani et al. (1995)	43.00% of individuals with thalassaemia (14-22 years) (n=90) reported currently being in a relationship vs 53.00% in comparison group (n=100).	A greater number of individuals in the comparison group reported currently being in a relationship compared with those with LTC-P.
	Zukerman et al. (2011)	59.00.% of individuals with SB (18-19 years) (n=52) reported currently being in a relationship vs 68.00.% in comparison group (n=60).	A greater number of individuals in the comparison group reported currently being in a relationship compared with those with LTC-P.
	Calsbeek et al. (2002)	49.10% of individuals (12-25 years) with inflammatory bowel disease in a partnership (n=305) vs 42.20% of individuals with chronic liver disease (n=94), 40.08% congenital digestive disorders (n=137), 56.70% with coeliac disease (n=94), 55.40% with food allergies (n=98) and 53.30% in a comparison group (n=306).	A similar number of individuals with coeliac disease and food allergies (independent samples) reported being in a partnership compared with comparison group. Fewer individuals with inflammatory bowel disease, chronic liver disease and congenital digestive disorders compared with comparison group.
	Gerhardt et al. (2007)	46.00% of individuals (15-22 years) post cancer diagnosis (survivors) (n=56) had a steady boyfriend or girlfriend vs 48.00% of comparison group (n=60).	A similar number of individuals in the comparison group reported having a steady boyfriend or girlfriend compared with those with LTC-P.

Relationship category	Study name and year	Percentages of individuals with Long-Term Physical Health Conditions (LTC-P) engaging/having engaged with different types of romantic relationships including similar percentages for comparison group(s) where provided	Comparison of Long-Term Physical Health Condition (LTC-P) group with normative comparison group with regard to relationship characteristics
Marriage	Gerhardt et al. (2011)	44.00% of participants (17-19 years) with Juvenile Idiopathic Arthritis (JIA) (n=45) had a steady boyfriend or girlfriend vs 43.00% comparison group (n=70).	A similar number of individuals with LTC-P reported having a steady boyfriend or girlfriend compared with comparison group
	Sodergren et al. (2018)	64.00% of 14-25 year olds with cancer (n=45) were living with a partner.	No comparison group.
	Thompson et al. (2009)	7.10% of individuals (18-25 years) post cancer diagnosis (survivors) (n=60) had ever lived with a partner vs 4.60% comparison group (n=60).	A similar number of individuals with LTC-P had ever lived with a partner compared with comparison group.
	Verhoef et al. (2000)	25.00% of individuals with SB (16-25 years) (n=83) currently had a partner, with 39.00% reporting previously having a partner.	No comparison group.
	Verhoef et al. (2005)	25.00% of individuals with SB (16-25 years) (n=157) currently had a partner.	No comparison group.
	Wiegerink et al. (2008)	19.00% of individuals with CP (16-20 years) (n=103) currently had a steady partner vs 46% comparison group. Of the 19%, 11.00% of males reported a steady girlfriend and 32.00% of girls reported a steady boyfriend.	No comparison group.
	Bussing & Aro (1996)	34.90% of 22 year olds with an ongoing LTC-P (n=423) were married or living with a steady partner vs 26.00% of comparison group (n=779).	A greater number of individuals with LTC-P were married/living together compared with comparison group.
	Canada et al. (2007)	4.76% of participants (15-25 years) were married (n=21).	No comparison group.
	Gerhardt et al. (2007)	5.00% of individuals (15-22 years) post cancer diagnosis (survivors) (n=56) were married vs 3.00% comparison group (n=60).	A similar number of individuals with LTC-P were married compared with comparison group.
	Gerhardt et al. (2011)	2.00% of participants (17-19 years) with JIA (n=45) were married vs 2.00% of comparison group (n=70).	Same percentage of individuals with LTC-P and members of the comparison group were married
	Thompson et al. (2009)	7.10% of individuals (18-25 years) post cancer diagnosis (survivors) (n=60) had ever been married vs 1.50% of comparison group (n=60).	A greater number of individuals with LTC-P had ever been married compared with comparison group.

<b>Relationship category</b>	<b>Study name and year</b>	<b>Percentages of individuals with Long-Term Physical Health Conditions (LTC-P) engaging/having engaged with different types of romantic relationships including similar percentages for comparison group(s) where provided</b>	<b>Comparison of Long-Term Physical Health Condition (LTC-P) group with normative comparison group with regard to relationship characteristics</b>
	Thompson et al. (2013)	5.56% of individuals (18-25 years) post cancer diagnosis (survivors) (n=18) were married and 5.56% of these individuals were divorced.	No comparison group.

\* Only studies that have reported data specifically about relationship characteristics are presented in this table.

